

**EXPERIENCES OF FAMILY MEMBERS CARING FOR A LONG
TERM MENTALLY ILL PATIENT AT LETABA, LIMPOPO
PROVINCE**

by

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in the subject

Health Studies

at the

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DECLARATION

I declare that **EXPERIENCES OF FAMILY MEMBERS CARING FOR A LONG TERM MENTALLY ILL PATIENT** is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references and that this work has not been submitted before for any other degree at any other institution.

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EXPERIENCES OF FAMILY MEMBERS CARING FOR A LONG TERM MENTALLY ILL PATIENT

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ABSTRACT

Qualitative, exploratory and descriptive research study was conducted using the case study approach. The purpose of this study was to explore and describe the experiences of family members caring for a long term mentally ill patient suffering from schizophrenia. Purposive sampling was used to select one family who cared for the patient for more than two years. Data was collected through the process of in-depth, unstructured individual interviews. Interviews were tape recorded and transcribed verbatim. Themes, categories and sub-categories were finally identified. The findings revealed that although the family was willing to care for the patient at home, they experienced challenges to provide basic care. Other challenges included were lack of adherence to treatment, financial constraints, substance abuse, social stigma, fear and concerns about the patient's future. A conceptual map was designed to reflect the major concepts of the findings.

KEY CONCEPTS

Caring, experiences, family members, long-term mentally ill patient, schizophrenia.

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Dedication

This study is dedicated to my husband, Eric Banyini, my two children, Shihlovo and Shihluke Banyini, for their support, encouragement and understanding.

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List of abbreviations

ANC	African National Congress
ID	Identify document
DSM- IV-TR	Diagnostic and Statistical Manual of Mental Disorder, Fourth Edition, Text Revision
MHCU	Mental Health Care User
PHC	Primary Health Care
SA	South Africa
SAPS	South African Police Service
USA	United States of America

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Annexure A

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CHAPTER 1

Orientation to the study

1.1 INTRODUCTION

Every individual aspires to good mental health. The provision of services for persons with mental health problems is a societal obligation. In South Africa (SA), the mental health component was integrated into the Primary Health Care (PHC) services with the implementation of the PHC approach (Mphelane 2006:1). The *Mental Health Care Act, 17 of 2002* refers to patients living with mental illness as mental health care users (MHCU) and stipulates the conditions of provision of care, treatment and rehabilitation for persons who are mentally ill (South Africa 2002:16-17). In terms of the Act, the person, human dignity and privacy of every MHCU must be respected. They must be provided with care, treatment and rehabilitation services that improve the MHCU's mental capacity to develop them to their full potential and to facilitate their integration into community life (South Africa 2002:16). Every person, body, organisation or health establishment providing care, treatment and rehabilitation services to MHCU must take steps to ensure that MHCU are protected from exploitation, abuse and any degrading treatment.

All individuals develop and live most of their lives within the context of a family system. The rehabilitation process should also include the family who care for the patient in the absence of the health care professionals. A family comprises of several members who have certain deeply ingrained roles which are defined by culture, class and gender (Mphelane 2006:1). The individual members, as well as the family also pass through various developmental life stages of their own. The symptoms of mental illness manifested by the mentally ill patients may represent signs of failure of the family system as a whole to adapt to internal and external changes (Baumann 2008:627). Family intervention is the most important milieu for the treatment and rehabilitation of patients living with mental illness. Relapse and hospitalisations may decrease due to family assistance intervention (Uys & Middleton 2010:430).

Before the identification of the biological basis of many major mental illnesses, families were blamed for the development of mental illnesses. Some families even delayed seeking medical advice when a family member became mentally ill through fear of criticism from health care professionals (Finkelman 2000:143).

Trump and Hugo (2000:5) found that public ignorance and the attitude of health care professionals led to people living with mental illness to delay seeking help and information with regard to medication for mental health-related problems. Moreover, the side effects of the drugs for patients living with mental illness were also not discussed with the affected families (Trump & Hugo 2000:5).

The families of patients living with mental illness face drastic changes in their lives, which require significant changes in behaviour and capacity to deal with strong emotions and problems that they encounter. Finkelman (2000:142) states that the families of patients living with mental illness struggle through their members' illness and their own feelings about the illness. They experience many feelings and problems together with their mentally ill family members over a long time (Finkelman 2000:142). Finkelman (2000:143) identifies objective and subjective burdens that the families carry. Objective burdens are concrete problems including financial problems, role changes, inadequate resources for support and treatment, and disruption in their personal lives. Subjective burdens result from excessive worry and concern that the family experience including anxiety, depression, grief, and physical health problems.

In the United States of America (USA), more than four million families live with severely mentally ill members (Kneisl & Trigoboff 2009:820). Kneisl and Trigoboff (2009:820) stress that caring for a mentally ill member is a very important, largely underappreciated, stigmatised, and frequently expensive, time-consuming and lifelong task. Furthermore, the family burdens reported most often are financial strain, violence in the household, reduction in the physical and mental health of family care givers, and disruption of family routines.

Mphelane (2006:4) found that a loved one's mental illness is experienced as a crisis for the family. The family find it difficult to accept the mental illness, find treatment, and cope with the mentally ill family member, who may be angry or withdrawn, while continuing to meet everyday responsibilities. Family members become frustrated,

exhausted and frightened even when the patient is stabilised on medication. Family life can be unsettled and unpredictable and it becomes difficult or often impossible to plan for family outings, vacations or even the simplest gatherings at home. The social state and health of family members deteriorate due to the stress and overwork and these result in the patient having no ongoing support system (Mphelane 2006:4-7).

Mphelane (2006:44) also found that many of the participants found it is a problem to support mentally ill relatives, and some relatives are no longer employed in order to care for the mentally ill member. Some family members were worried about the future and the impact of their stigma on their own social lives. The mental health treatment system itself is experienced as a stressor and the family often feels overwhelmed or unable to cope. However, without the family's active participation and involvement in the care of their relatives, little progress can be made in improving the health status of their mentally ill relative.

1.2 BACKGROUND TO THE STUDY

Letaba Hospital is a provincial psychiatric hospital in the Limpopo Province, South Africa, which oversees six district hospitals, namely Sekororo, Maphuta Malatjie, Evuxakeni, Dr CN Phatudi, Nkhensani and Van Velden Hospitals including clinics and villages catered for by these hospitals. Letaba Hospital is designated to admit mentally ill patients for short- and long-term care. It has one psychiatrist, three medical practitioners, ten professional psychiatric nurses, five enrolled nurses and twenty enrolled nursing auxiliaries (see table 1.1).

Table 1.1 Health care professionals in Letaba Hospital Psychiatric Unit, 2011

CATEGORY	NUMBER
Psychiatrist	1
Medical practitioners	3
Professional psychiatric nurses	10
Enrolled nurses	5
Enrolled nursing auxiliaries	20
TOTAL	39

The most common mental illnesses noted at the Letaba Hospital are schizophrenia, psychoses, bipolar mood disorders, and substance abuse disorders. Of these illnesses, schizophrenia is the most frequently diagnosed mental illness (see tables 1.2 and 1.3).

Table 1.2 Number of mentally ill patients with specific mental illnesses from January to June 2011

MENTAL CONDITION	JANUARY	FEBRUARY	MARCH	APRIL	MAY	JUNE	TOTAL
Schizophrenia	26	25	21	15	21	21	129
Psychosis	8	6	7	10	9	14	54
Bipolar mood disorder	8	7	6	8	4	7	40
Substance abuse	3	4	6	3	4	5	25
TOTAL	45	42	40	36	38	47	248

(Letaba Hospital Admission Register 2011)

Table 1.3 Number of mentally ill patients with specific mental illnesses from July to December 2011

MENTAL CONDITION	JULY	AUGUST	SEPTEMBER	OCTOBER	NOVEMBER	DECEMBER	TOTAL
Schizophrenia	21	20	16	15	20	13	105
Psychosis	9	8	9	11	8	10	55
Bipolar mood disorder	7	6	5	5	4	6	33
Substance abuse	12	8	6	5	4	4	39
TOTAL	49	42	36	36	36	33	232

(Letaba Hospital Admission Register 2011)

Tables 1.2 and 1.3 indicate an increase of mentally ill patients over the year 2011, particularly with schizophrenia patients. This emphasises that more families are being affected in ways that undermine the person's quality of life.

1.3 RESEARCH PROBLEM

Burns and Grove (2009:68) define a research problem as “an area of concern where there is a gap in the knowledge base needed for nursing practice”. It can be identified by asking questions such as the following:

- What is wrong or is of concern in this clinical situation?
- What information is needed to improve this situation?

Research problems are developed from many sources, including social issues; clinical ethical dilemmas; observed health and illness patterns; interaction with colleagues, individuals and communities; nursing practice, and nursing literature (Brink, Van der Walt & Van Rensburg 2008:59; Burns & Grove 2009:70; Polit & Beck 2008:821).

In this study, clinical observation of the behaviour of relatives who brought mentally ill patients to hospital, and during questioning and interviewing during history taking has led the researcher to question what interventions could be used to improve the family's coping skills. For example, when patients living with mental illness fail to follow the treatment plan provided by their nurse or medical practitioners this creates difficulties for the family members to cope.

A setting is the location where a study is conducted (Burns & Grove 2009:35). This study was conducted in a natural or real-life setting, namely the home setting of a family of a long-term mentally ill patient treated in Letaba Hospital, Mopani District in Tzaneen of Limpopo Province. The home is the natural setting for the patients as it is where they deal with everyday problems and truly interact with the family and other members of the community. Helping the family cope with problems of this nature in this environment is usually a more effective resource as they have a better understanding and offer collateral of the effects of the illness on the patient and family life.

1.4 PURPOSE OF THE STUDY

The purpose of the study was to investigate the experiences of families of a long-term mentally ill patient in terms of what the situation means to them, the challenges experienced, and the coping skills that they utilised.

From the literature review on the phenomenon under study, the researcher identified a need for further empirical investigation of the experiences encountered by families as they care for long-term mentally ill patients. Therefore, the study wished to answer the question:

- What are the experiences of family members caring for a long-term mentally ill patient?

1.5 OBJECTIVES

In order to answer the research question, the objectives of this study were to:

- explore and describe the experiences of family members caring for a long-term mentally ill patient
- identify challenges and coping mechanisms utilised by family members to deal with the situation
- create awareness of health care providers about the experiences of families of a long-term mentally ill patient
- develop a conceptual map to depict a pattern of the experiences of family members caring for a long-term mentally ill patient

1.6 SIGNIFICANCE OF THE STUDY

Research is conducted to generate knowledge that will directly influence or improve clinical practice (Burns & Grove 2009:34). This study should generate knowledge that will enable health care professionals working in psychiatric units to understand the family members' experiences when caring for long-term mentally ill patients and to give them professional and supportive services in managing mental illness at home. This should further assist health care providers to improve the support and care for such families. The findings should contribute to clarifying the role of the family members in the continuity of care for the mentally ill care users to prevent relapses and re-hospitalisations.

In-service education programmes, health education talks with family members, and the training of students should also benefit from this study. Finally, the findings should assist in the formulation of protocols, policies and documentation of discharge plans and approaches to caring for affected mentally ill patients and family members at home.

1.7 FOUNDATIONS OF THE STUDY

The foundations of a study refer to the philosophical base, concepts, and theories utilised, while a theoretical framework is “an abstract, logical structure of meaning that guides the development of the study and enables the researcher to link the findings to the nursing body of knowledge” (Burns & Grove 2009:60). Brink et al (2008:24) state that a theoretical framework “is based on propositional statements resulting from an existing theory”. In this study, no particular framework was used as the researcher developed a conceptual map that depicted a pattern of the experiences of family members as they care for a patient living with mental illness.

1.8 META-THEORETICAL, THEORETICAL AND METHODOLOGICAL ASSUMPTIONS

Assumptions are basic principles that are assumed to be true based on logic and reason, without proof or verification (Mouton & Marais 1994:11; Polit & Beck 2008:13-14). Sources of assumptions include universally accepted truths such as theories, previous research and nursing practice. In research, assumptions are embedded in the philosophical base of the framework, study design and interpretation of the findings (Burns & Grove 2009:40). Assumptions influence the logic of the study and their recognition leads to more rigorous study development. Epistemological, ontological and methodological assumptions were posited in this study.

Epistemological assumptions are assumptions about the nature of knowledge and science or about the content of truth and related ideas (Mouton 2002:123). In this study, the epistemological assumptions were as follows (Mouton 2002:123):

- Multiple realities exist with regard to caring for a long-term mentally ill patient and this can be captured by means of qualitative research.

- Narrative data can elicit an understanding of the meanings that family members attach to caring for a long-term mentally ill patient.
- Although it is difficult to ascertain when the truth has been attained, it is, however, necessary to strive for reality as closely as possible.
- Theories inductively generated from data are likely to offer insight and knowledge, enhance understanding, and provide a meaningful guide to action, including nursing practice.

Ontological assumptions refer to the study of human nature, society, the nature of history, the status of mental entities, and observable and material phenomena in human action behaviours (Mouton 2002:124). The ontological assumptions underlying this study were as follows:

- Each person functions as a holistic being who acts on, interacts with, and reacts to the environment as a whole person (Stuart 2009:7).
- All people have common basic human needs which include physical requirements, safety, love, belonging, esteem and self-actualisation.
- The behaviour of an individual is meaningful as it arises from personal needs and goals.
- Caring for a long-term mentally ill patient has different meanings to individuals.
- Individuals vary in their coping capacities; depend on their genetic endowment, environmental influences, nature and degree of stress, and available resources.
- All persons are valued and have a right to equal opportunity for adequate health care regardless of gender, race, religion, ethics and cultural backgrounds.
- The meaning attributed by the mentally ill patient and families to illness impacts heavily on their demands on the health care services, and the nurses' approach to care.

Methodological assumptions refer to assumptions about the nature of the research process and the most appropriate methods and research procedures to be used (Mouton 2002:124). They refer to the logic of implementing scientific methods in the study of reality. The methodological assumptions in this study were as follows:

- Qualitative research supports naturalistic inquiry to collect narrative data on reality, which is constructed by people.
- In-depth interviews are ideal in conducting a qualitative inquiry into a specific phenomenon.

Burns and Grove (2009:40) state that assumptions are embedded in thinking and behaviour, and uncovering these assumptions requires introspection and a strong knowledge base in the particular field of study.

1.9 RESEARCH DESIGN

A research design is the set of logical steps taken by the researcher to answer the research question (Brink et al 2008:92). A research design is an overall plan for obtaining answers to research questions (Polit & Beck 2008:66). The researcher used a qualitative, explorative and descriptive case study design in this study.

1.9.1 Qualitative

Qualitative research is a systematic, interactive, subjective approach used to describe the life experiences of the participants and to give them meaning (Burns & Grove 2009:22). The researcher selected a qualitative design in order to investigate the experiences of family members caring for a long-term mentally ill patient (see chapter 3).

1.9.2 Exploratory

According to Polit and Beck (2008:20), exploratory research begins with a phenomenon of interest and explores the full nature of the phenomenon. De Vos, Strydom, Fouche and Delport (2005:106) state that explorative research is conducted to obtain basic information about an area of interest. An exploratory approach was considered appropriate to explore the participants' experiences (see chapter 3).

1.9.3 Descriptive

A descriptive design enables the researchers to describe variables in order to answer research questions, with no attempt at establishing a cause-effect relationship (Brink et al 2008:102). This study was descriptive because the researcher wished to describe the participants' experiences (see chapter 3).

1.10 RESEARCH METHODOLOGY

The research methodology describes the techniques and research procedures followed when conducting a study, including the population, sample and sampling, data collection and analysis, trustworthiness and ethical considerations (see chapter 3 for detailed discussion).

1.10.1 Population

A research population refers to all the elements (individuals, objects or substances) that meet certain criteria for inclusion in a given universe (Burns & Grove 2009:42). In this study, the population was all family members caring for a long-term mentally ill patient.

1.10.2 Sampling

Non-probability sampling methods are used in qualitative research and not every element of the population has an opportunity to be included in the sample (Burns & Grove 2009:353; Polit & Beck 2008:341). Purposive sampling was used to recruit a family sample for the study. Burns and Grove (2009:355) describe purposive sampling as "judgmental or selective sampling that involves the conscious selection by the researcher of certain participants, elements, events or incidents to include in a study". It is most commonly used in qualitative research and was suitable in this study because only one family that met the inclusion criteria was selected.

1.10.3 Case study

A case study is defined by Bowling (2002:403) as a research method which focuses on the circumstances, dynamics and complexity of a single case, or a small number of

cases. In this study it will be used for an in-depth investigation of the experiences of a family caring for a long term mentally ill patient.

1.10.4 Data collection

Data was collected through in-depth individual interviews with one family caring for a long-term mentally ill patient. An interview is a “structured or unstructured oral communication between the researcher and the participant, during which information is obtained for the study” (Burns & Grove 2009:705). An interview guide was designed and utilised to collect data in the home setting of the participants.

1.10.5 Data analysis

Data analysis is a process of bringing order, structure and meaning to the mass of collected qualitative data (De Vos in De Vos et al 2005:333). Data in qualitative research is non-numerical and is usually in the form of written or audio-taped information (Brink et al 2008:184). In this study the researcher used Tesch's eight-steps of data analysis method (Creswell 1994:155).

1.11 MEASURES TO ENSURE TRUSTWORTHINESS

The researcher followed Lincoln and Guba's (1985:289-331) method and standards for qualitative studies to ensure trustworthiness of the study, namely credibility, transferability, dependability and confirmability (see chapter 3).

1.12 ETHICAL CONSIDERATIONS

Ethics refers to a set of moral principles which is suggested by an individual or group and offers rules and behavioural expectations about the correct conduct towards the participants (Strydom in De Vos et al 2005:57). Ethical guidelines serve as standards and a basis on which researchers evaluate their own research conduct. The ethical standards that were maintained included protection of the rights of the institution, participants and scientific integrity.

1.12.1 Protecting the rights of the institution

The researcher protected the rights of the institution by obtaining permission to conduct the study from the Provincial Research Ethics Committee and the Ethics Committee of the Department of Health Studies at the University of South Africa. Permission was also obtained from Letaba Hospital to identify a family of a long-term mentally ill patient from the hospital records.

1.12.2 Protecting the rights of the participants

The researcher protected the rights of the participants by upholding the principles of informed consent and voluntary participation, anonymity, confidentiality, respect and dignity, and the right to withdraw from the study at any stage (see chapter 3).

1.12.3 Scientific integrity

The researcher ensured the scientific integrity of the study by no fabrication, falsification or forging of information; presenting a true reflection of the results and findings, and acknowledging all sources of information (Brink et al 2008:40).

1.13 SCOPE AND LIMITATIONS OF THE STUDY

This study was of limited scope because it was restricted to a single family identified in one hospital only, consequently it will not be possible to generalise the findings.

1.14 DEFINITIONS OF KEY CONCEPTS

For the purposes of this study, the following terms are used as defined below:

- **Caring.** Caring is a process of providing a substantial amount of care or support on a regular basis to another person, because of age, disability or illness, when managed in an institution or at home (*Blackwell's Nursing Dictionary* 2005:109).

In this study, caring refers to care and support provided by relatives or family members at home, to a long-term mentally ill patient who was treated at a

psychiatric hospital for over two years without any contract of employment or payment.

- **Experience.** Experience is practical knowledge of any matter gained by trial, long and varied observation (*The Chambers English Dictionary* 2006:529). *Collins English Dictionary and Thesaurus* (1995:395) define experience as “direct personal observation; a particular incident or feeling that a person has undergone; accumulated knowledge of practical matters”.

In this study experience refers to the knowledge that the family members have acquired while caring for their mentally ill relative.

- **Family.** *Concise Oxford English Dictionary* (2006:513) defines a family as “a group of people related by blood or marriage”. Valfre (2001:409) defines a family as “a group of people who are biologically or emotionally attached, interact regularly, and share concerns for the growth and development of each member”.

Stuart and Laraira (2005:862) describe a family as “a group of people living together in a household who are attached emotionally, interact regularly and share concerns for the growth and development of individuals and the family”.

In this study a family consists of members of a particular selected household or close relative that have been taking care of a long-term mentally ill patient for at least two years.

- **Health.** Mandle (2010:7) defines health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity”. Good health promotes physical, mental and social development, and development promotes complete health.
- **Long-term mentally ill patient.** *Baillière's Nurse's Dictionary* (2005:295) defines a patient as “a person who is physically or mentally ill or is undergoing treatment for a health care problem and / or is registered with a general practitioner”.

A MHCU is defined by the Mental Health Act, 17 of 2002 (South Africa 2002:10) as “a person receiving care, treatment and rehabilitation services or is using a health care service at a health establishment aimed at enhancing the mental health status of a user”.

In this study, a long-term mentally ill patient is a person who has been institutionalised in a psychiatric hospital for over two years, had repeated admissions for mental illness, and is receiving care, treatment and rehabilitation services at the hospital. The terms psychiatric patient and mentally ill patient were used interchangeably in this study.

- **Schizophrenia.** Uys and Middleton (2010:412) define schizophrenia as “a term used to describe a group of complex, severe conditions that are the most chronic and disabling of the mental illnesses”.
- **Mental illness.** In terms of the *Mental Health Care Act, 17 of 2002* (South Africa 2002:10), mental illness means “a positive diagnosis of a mental health-related illness in terms of accepted diagnostic criteria selected by a mental health care practitioner authorised to make such a diagnosis”.

Conceptual and operational definition of concepts assist researchers with conceptual clarity and construct validity.

1.15 STRUCTURE OF THE DISSERTATION

Table 1.4 outlines the structure of the dissertation.

Table 1.4 Structure of the dissertation

Chapter	Title	Content description
1	Orientation to the study	An overview of the research problem, purpose and significance of the study, research design and methodology, including measures to ensure trustworthiness, ethical considerations, and definition of key concepts.
2	Literature review	Discussion of the literature reviewed on the topic.
3	Research design and methodology	Description of the research design and methodology used, including data-collection techniques.
4	Data analysis and interpretation	Presentation of data analysis and results.
5	Conclusion and recommendations	Findings and recommendations.

1.16 CONCLUSION

This chapter outlined the problem, purpose and significance of the study, as well as the research design and methodology, including the population, data collection and analysis, and ethical considerations. Key terms were defined and an outline of the dissertation given.

Chapter 2 discusses the literature review conducted for the study.

CHAPTER 2

Literature review

2.1 INTRODUCTION

A literature review is used first and foremost in the contextualisation of a study to argue a case or identify a niche to be occupied by the research (Henning 2004:27). A good literature review lays the foundation for the research as it generates a picture of what is known and not known about the research problem. Burns and Grove (2009:92) state that a literature review is an organised, written presentation of what has been published on a topic. The purpose of the review is to convey to the reader with what is currently known regarding the topic of interest.

A literature review refers to a scrutiny of all relevant sources of information. It is an excellent source for selecting or focusing on a topic, as it reduces the chances of selecting an irrelevant or outdated topic by investigating what has already been done in a particular problem area. The researcher also ensures that nobody else has already performed what is essentially the same research. It further demonstrates the underlying assumptions of the general research questions and that the researcher is knowledgeable about related research (Fouche & Delport in De Vos et al 2005:124-127).

The literature review helps the researcher to develop relevant study methods and instruments or tools with which to measure the study variables (Brink et al 2008:52). The review should be comprehensive and cover relevant journal articles, books, reports, dissertations and theses.

The literature review in this study focused on issues specifically relevant to family members' experiences in caring for a long-term mentally ill patient.

2.2 MENTAL HEALTH

Health is defined as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (Mandle 2010:7). Good health promotes physical, mental and social development, and development promotes complete health.

Mental health is often said to be a state of well being associated with happiness, contentment, satisfaction, achievement, optimism and hope (Stuart 2009:46). Mental health is further defined as an integral part of health, and there is no health without mental health. It is a state of well being in which an individual realises his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully , and is able to make a contribution to his or her community (Uys & Middleton 2010:17).

Stuart (2009:46) identifies six criteria of mental health:

- Positive attitudes towards self include an acceptance of self, and self-awareness.
- Growth, development and self-actualisation means that individuals seek new experiences to fully explore more aspects of themselves.
- Integration is a balance between what is expressed and what is repressed between outer and inner conflicts.
- Autonomy involves self-determination, a balance between dependence and independence and an acceptance of the consequences of one's actions.
- Reality perception is the individual's ability to test assumptions about the world by empirical evidence.
- Environmental mastery enables a mentally healthy person to achieve success in an approved role in society (Stuart 2009:46).

A person should not be assessed against some information on health; rather each person should be seen in both a group and an individual context. The issue is not how well someone fits into social cultural standards, but what is reasonable for a particular person (Stuart 2009:46).

2.3 MENTAL ILLNESS

In terms of the *Mental Health Care Act, 17 of 2002* (South Africa 2002:10), mental illness refers to a positive diagnosis of a mental health-related illness, in terms of accepted diagnostic criteria made by a mental health care practitioner authorised to make such a diagnosis. Sadock and Sadock (2007:15) describe mental illness as a medical disease that can be distinguished on the basis of pathophysiological causes. Certain mental illnesses are found throughout the world and within every culture; for example, schizophrenia is universally prevalent (Sadock & Sadock 2007:15).

2.3.1 Characteristics of serious mental illness

People who have serious mental illnesses are likely to have primary and secondary symptoms (Stuart 2009:202). Primary symptoms are directly caused by the illness; for example, hallucinations and delusions are primary symptoms of schizophrenia. Secondary symptoms such as loneliness and social isolation are caused by the person's response to the illness or its treatment (Stuart 2009:202). Behaviours related to primary symptoms may violate social norms and be considered deviant, and as behaviour problems become more serious, people identify themselves as mentally ill and begin to relate to society in terms of this identity rather than as wife, husband, child, mother, father or worker. The person's acceptance of the mentally ill status and adjustment to society in terms of this role are accompanied by the secondary symptoms of serious mental illness (Stuart 2009:202).

2.3.2 Behaviours related to serious mental illness

Roadblocks to the recovery of individuals with severe mental illness include poverty, victimisation and stigma. People with serious mental illness are often unemployed, are less likely to be involved in close relationships, and have fewer financial resources than their peers (Stuart 2009:202).

According to Stuart (2009:202), the following behaviours are likely to be exhibited by a mentally ill patient:

- *Disturbances related to activities of daily living* which are the skills necessary to live independently, such as housekeeping, shopping, food preparation and personal hygiene.
- *Interpersonal relations* where people with mental illness are often described as apathetic, withdrawn and socially isolated; for instance schizophrenia leads to problems in perceiving and processing communications from others.
- *Low self-esteem* which is a feeling of their low self-worth or low regard for oneself. Because of their low achievement as compared to cultural expectations, it is difficult for mentally ill people to maintain a high self-esteem. They lack the ability to maintain employment, live independently, marry and have children. They feel cheated of quality life experiences as they expected to enjoy before they became ill. Fear of failure results in reluctance to try new experiences and is perceived by others as a lack of motivation, although a *lack of motivation* can also be related to the biological effects of the illness or to the medication.
- *Lack of strength* which is the ability, skill or interest that a person used before the illness and an emphasis on strengths provides hope that improved functioning is possible.
- *Non-adherence* which is the failure to comply with medication take is a common cause of rehospitalisation. The reasons for non-adherence are varied and should be assessed. They may be related to denial of the illness, lack of understanding of the treatment regimen, patient needing help such as transportation to hospital, and the side effects of the medication.

2.3.3 Misconceptions about mental illness

The following misconceptions can contribute to family and community attitudes towards the support and care of mentally ill people (Stuart 2009:203):

- People with a severe mental illness such as schizophrenia are usually dangerous and violent.
- Mental illness is a result of bad parenting.
- Schizophrenia is sometimes known as split personality and there is no way to control it.

- Treatment for a mental disorder means an individual has in some way failed or is weak.

Public and professional misconceptions about mental illness may make families of people with mental illness like schizophrenia apprehensive, about acknowledging the diagnosis of their relative. Having a diagnostic label is good, since it provides information to those affected and allows them to make informed decisions and manage the illness. On the contrary the labelling process may lead to negative stereotypes of the mentally ill and discrimination (Uys & Middleton 2010:86). A person diagnosed with schizophrenia increases the perceptions that the person is dangerous and leads to emotions of fear and anger.

2.3.4 The rights of people with mental illness

Chapter III of the *Mental Health Care Act, 17 of 2002* (South Africa 2002:16-22) stipulates that mentally ill people have the following rights in addition to any rights under other legislations:

- **Respect, human dignity and privacy**

The person, human dignity and privacy of every MHCU must be respected and the services administered to them must be proportionate to their mental health status, and may intrude only as little as possible to give effect to the appropriate care, treatment and rehabilitation (South Africa 2002:16).

- **Consent to care, treatment and rehabilitation services and admission to health care establishments**

A MHCU must consent to the care, treatment and rehabilitation services or to admission unless due to mental illness, any delay in providing care, treatment and rehabilitation services or admission may result in the death of or irreversible harm to the health of the user and others. Care, treatment and rehabilitation services may not be used as punishment or for the convenience of other people (South Africa 2002:18).

- **Unfair discrimination**

A MHCU may not be unfairly discriminated against on the grounds of his or her mental health status, and must receive care, treatment and rehabilitation services according to the standards equivalent, to those applicable to any other health care user (South Africa 2002:18).

- **Disclosure of information**

A person or health establishment may not disclose any information which a MHCU is entitled to keep confidential in terms of any other legislation (South Africa 2002:20).

2.4 SCHIZOPHRENIA AS A LONG-TERM MENTAL ILLNESS

Kneisl and Trigoboff (2009:370) define schizophrenia as a complex disorder with an extremely varied presentation of symptoms. Uys and Middleton (2010:412) describe it as a group of complex, severe conditions that are the most chronic and disabling of the mental illnesses. The symptoms may differ from person to person, but in order to be diagnosed, an individual must have experienced the presenting symptoms for at least six months (Kneisl & Trigoboff 2009:371).

Schizophrenia is found in all societies and geographical areas. It is equally prevalent in men and women although they differ in the onset and the course of the illness. The onset of the illness is earlier in men than in women. Men tend to become ill in their twenties, while women become ill in their thirties. During one's lifetime approximately 1% of the population may develop schizophrenia (Kneisl & Trigoboff 2009:371; Sadock & Sadock 2007:468; Uys & Middleton 2010:413).

The use of psychopharmacological drugs, the open door policy in hospitals, the deinstitutionalisation in state hospitals and the emphasis on rehabilitation and community-based care for patients, have led to an increase in marriage and fertility rates among persons with schizophrenia (Sadock & Sadock 2007:469). The fertility rate for persons with schizophrenia is close to that for the general population and their rights have changed the patterns of hospitalisation. Although the *Mental Health Care Act*, 17

of 2002 (South Africa 2002:20) states that the head of a health establishment may limit intimate relationships of adult MHCU, mentally ill patients do engage in sexual activities.

Because of the genetic contributions, schizophrenia occurs at an increased rate among the biological relatives of patients with schizophrenia. Children with schizophrenic parents have a 10% chance of developing schizophrenia compared to the 1% risk of persons in the general population (Kneisl & Trigoboff 2009:379; Sadock & Sadock 2007:470; Uys & Middleton 2010:413).

2.4.1 Symptoms of schizophrenia

The symptoms of schizophrenia are separated into positive symptoms, which represents an excess or distortion of normal functioning, and negative symptoms, which represents a deficit in functioning (Kneisl & Trigoboff 2009:371; Stuart 2009:336; Uys & Middleton 2010:420).

Positive symptoms include the three most pronounced outward signs of the disorder: hallucinations, delusions, and disorganisation in speech and behaviour. Hallucinations are the most extreme and most common perceptual disturbance in schizophrenia. A hallucination is a subjective sensory experience that is not actually caused by external sensory stimuli. Hallucinations may be auditory, visual, olfactory, gustatory, or tactile and the most common form of hallucination in schizophrenia is auditory hallucinations (Kneisl & Trigoboff 2009:371; Stuart 2009:336; Uys & Middleton 2010:420).

The negative symptoms of schizophrenia are less dramatic but are as debilitating as the positive symptoms. The negative symptoms of schizophrenia include a flat affect, alogia, avolition and anhedonia (Kneisl & Trigoboff 2009:371; Stuart 2009:336).

2.4.2 Diagnosis of schizophrenia

Black South African patients are frequently inappropriately given a diagnosis of schizophrenia (Uys & Middleton 2010:413). This is due to cultural beliefs which are misunderstood by Western health care workers and also as a result of communication and translation problems. Adequate attention is not given to eliminate other conditions which present similarly to schizophrenia, such as syphilis and temporal lobe epilepsy

(Uys & Middleton 2010:413). Persons with schizophrenia have a higher mortality rate from accidents and natural causes, than the general population because concurrent their medical illnesses may be undiagnosed. In addition, there is a disparity of health care for patients with severe mental illness with little regard to providing basic physical health screening , treatment and monitoring for the individuals concerned (Stuart 2009:343).

2.4.3 Diagnostic criteria for schizophrenia according to Diagnostic and Statistical Manual of Mental Disorders, 4th edition, Text Revision (DSM-IV-TR)

The diagnosis of schizophrenia requires not only the presence of distinct symptoms but also the persistence of those symptoms over time. The symptoms must be present for at least 6 months and active phase symptoms called Criterion A symptoms must be present for at least 1 month before schizophrenia can be diagnosed (Kneisl & Trigoboff 2009:371).

The DSM-IV-TR (Kneisl & Trigoboff 2009:371) describe the diagnosing of schizophrenia according to the following criteria:

- (a) *Characteristic symptoms:* Two or more of the following symptoms which should be present for a significant portion of time during a period of 1 month or less if successfully treated:

- 1 delusions
- 2 hallucinations
- 3 disorganized speech such as frequent derailment or incoherence
- 4 grossly disorganized or catatonic behaviour
- 5 negative symptoms, evidenced by affective flattening, alogia, or avolition

Only one Criterion A symptom is required where the delusions are bizarre or the hallucinations consists of a running commentary of a “voice” on the person’s behaviour or thoughts, or where two or more “voices” are conversing with each other.

- (b) *Social and occupational dysfunction:* For a significant portion of the time since the onset of the mental disturbance, one or more major areas of functioning such

as work, interpersonal relations, or self-care are markedly reduced below the level achieved prior to the onset of the disturbance more often when the onset is during childhood or adolescence, failure to achieve expected level of interpersonal, academic, or occupational achievement is experienced.

- (c) *Duration:* Continuous signs of the mental disturbance persist for at least 6 months. This 6-month period must include at least 1 or less month of symptoms if that were successfully treated, that may meet Criterion A and that may include periods of the presence of prodromal or residual symptoms. During these prodromal or residual periods, the mental signs of the disturbance may be manifested by negative symptoms or by two or more symptoms listed in Criterion A which are present in an attenuated form such as odd beliefs and unusual perceptual experiences.
- (d) *Schizoaffective and mood disorders exclusion:* Schizoaffective and mood disorders with psychotic features may be ruled out if either (1) no major depressive, manic, or mixed episodes have occurred concurrently with the active symptoms phase, or (2) if the mood disorder episodes have occurred during the active symptom phase and their total duration has been relatively brief compared to the duration of the active and residual periods.
- (e) *Substance or general medical conditions exclusion:* The mental disturbance is not due to the direct physiological effects of substance abuse of a medication or due to a general medical condition.
- (f) *Relationship to a pervasive development disorder:* If there is a history of autistic disorder or another pervasive developmental disorder, the additional diagnosis of schizophrenia is only made if prominent delusions or hallucinations are also present for at least a month or less duration and if successfully treated (Kneisl & Trigoboff 2009:371).

Schizophrenia is a serious and persistent neurobiological brain disease that impairs the lives of individuals, their families and their communities (Stuart 2009:334). Table 2.1 lists the common neurobiological responses symptoms triggers related to health, the environment, and attitudes or behaviours.

Table 2.1 Neurobiological response symptom triggers

HEALTH	ENVIRONMENT	ATTITUDES/BEHAVIOURS
Poor nutrition	Hostile	Low self-concept
Lack of sleep	Housing difficulties	Lack of self-confidence
Fatigue	Loss of independent living	Loss of motivation to use skills
Infection	Changes in life events	Lack of control
Lack of exercise	Interpersonal difficulties	Feeling overpowered by symptoms
Barriers to accessing health care	Disruptions in interpersonal relationships Social isolation Lack of social support Poor occupational skills Stigmatisation Poverty Lack of resources Inability to get or keep a job	Unable to meet spiritual needs Looks or acts differently from others who are of the same age and culture Poor social skills Aggressive behaviour Violent behaviour Poor medication management Poor symptom management

(Adapted from Stuart 2009:348)

Patients with schizophrenia can learn to recognise the response symptom triggers that they are particularly reactive to and they can be taught to avoid them (Stuart 2009:348).

The brain is the organ that enables people to relate to the outside world. Patients with schizophrenia often have altered interpersonal relationships and; they are focused on internal processes to the extent that their external social world collapses (Keltner, Schwecke & Bostrom 2003:318).

2.4.4 Coping mechanisms

In the acute phase of psychosis, patients use several unconscious defence mechanisms, in an attempt to protect themselves from the frightening experiences

caused by the illnesses. They undergo **regression** related to the problem of information processing. This uses a large amount of their own energy to manage the anxiety leaving them little energy for activities of daily living. **Projection** occurs as an effort to explain their own confusing perceptions by assigning the responsibility to their behaviour, someone or something (Stuart 2009:348).

Withdrawal behaviour occurs mainly in the passive form; whereby the patients avoid contact and contribute poorly to conversation with others (Uys & Middleton 2010:419). Withdrawal behaviour is probably the result of interaction amongst three factors:

- The patient had limited social skills and developed few relationships even before becoming ill.
- Failure to establish relationships with people might have contributed to the patient becoming mentally ill.
- Long periods of hospitalisation in psychiatric units where social stimulation was limited and long periods spent doing no activities resulting in withdrawal.

Patients used withdrawal as a coping mechanism to defend themselves against intrusive, critical and overstimulatory interactions (Kneisl & Trigoboff 2009:386; Stuart 2009:226; Uys & Middleton 2010:419).

Mohammad, Subhi, Jusoff, Wan Azreena, Chong, Fauziah, Lukman, Sarnon, Nen, Hoesni and Alavi (2011:2) found that family caregivers developed strategies to cope with a long-term caring situation with a patient, using hope and faith; practical coping; emotional coping; detachment, and cultural coping mechanisms.

Hope and faith. To continue with the caring of the patient, family caregivers used hope and faith to motivate them in the long term situation.

- *Practical coping.* Family caregivers also take practical action by sharing their problems with other interested individuals especially with mental health professionals, and as they believed it would help them solve the problems that they had experienced when caring for their mentally ill relatives.

-
- *Emotional coping.* Some of the caregivers used positive and constructive thinking to cope with the negative emotions experienced. They believed that they had a commitment and responsibility to remain positive to the mentally ill patient.
- *Detachment.* Some family members used detachment by thinking of other matters instead of the mentally ill patient.
- *Cultural coping.* Caregivers used cultural care giving which included traditional coping when dealing with mental illness, because of existing cultural beliefs and the availability of resources in the community.

The findings of the study conducted by Mohammad et al (2011:5) further revealed that caregivers viewed their experience positively when they received continuous social support from the mental health professionals, their family members and their closest friends.

2.4.5 Self-care deficits

Schizophrenic patients appear indifferent to their personal appearance. Their diminished drive, flat affect and disturbances of thought are reasons associated with the patients having difficulty in accepting responsibility for their own self-care. Patients may neglect to bathe, change their clothes or attend to minor grooming tasks such as combing their hair. Some are not aware of the current fashion styles and wear clothing that makes them look out of place. Other patients wear clothing that is inappropriate to the current season and weather conditions (Kneisl & Trigoboff 2009:386).

The disregard for their appearance and hygiene may extend to the patients environment and the patient may fail to maintain a clean and safe living space. Schizophrenic patients may not take care of their personal belongings and may misplace them easily (Kneisl & Trigoboff 2009:386).

2.4.6 Deinstitutionalisation

Deinstitutionalisation refers to the transfer of a patient hospitalised for extended periods of time to a community setting. In the mental health care system, it refers to a shift in the focus from long-term institutional care to community care, accompanied by the

discharging of long-term patients home and by avoiding unnecessary admissions back to the institutions (Stuart 2009:629). Keltner et al (2003:7) refer to deinstitutionalisation as the depopulating of state mental hospitals. In 1977 Fuller Torrey cited in Keltner et al (2003:7) stated that “The practice, over the past four decades, of releasing people with mental illness from institutions has been one of the largest social experiments in twentieth century America”. Psychiatric services in general hospitals have become vulnerable to downsizing or closure (Keltner et al 2003:8; Stuart 2009:616). Only patients who require a high level of care, have few relationships, are psychotic and are acutely ill qualify to be hospitalised (Keltner et al 2003:8).

Most of mentally ill patients in South Africa live with their families to reduce hospitalisation, so that even a schizophrenic patient could spend more time in the community than the hospital (Uys & Middleton 2010:430).

Although deinstitutionalisation achieved a reduction in beds, admissions in hospitals increased, due to the increase in repeat criminal offenders and the emergency departments being used by acutely psychotic patients. Inadequate community resources also led to patients requesting to be re-admitted so that their basic needs could be met in the hospital. Keltner et al (2003:9) add that today's mentally ill patients are more aggressive and are armed with weapons than previously.

2.4.7 Concerns regarding deinstitutionalisation

With regard to deinstitutionalisation, Kotze (2007:27-28) indicates the following principal concerns:

2.4.7.1 Indiscriminate discharges

Indiscriminate discharges where the pressure to reduce patient admissions led to the discharge of patients without careful assessment of their readiness for discharge.

2.4.7.2 Inadequate family and community preparation and support

Family members need support to manage and accept the discharged mentally ill patient at home. They may experience difficulties in obtaining chronic medication and disability grants. Long-term assistance is needed for maintaining the discharged mentally ill patient at home.

2.4.7.3 Inadequate community resources

The availability of community resources may be helpful to lessen the burden of caring for a mentally ill relative. Drop-in centres and day care facilities or assistance can help family members who are working and when they want to need to attend to other matters.

2.4.7.4 Neglect and abuse

Mentally ill patients may be neglected by family members, due to the lack of community resources to monitor the discharged patients. Disability grants may be used to support the whole family and the mentally ill patients are sometimes left to beg for food to eat (Kotze 2007:27-28).

2.4.8 Homelessness

Homelessness is most often a problem for mentally ill people and this can be linked directly to deinstitutionalisation (Keltner et al 2003:9). Because of poor social support systems, some mentally ill patients leave home and wander on the streets. They survive on the streets by being aggressive and assaulting people passing by. From aggressive panhandling to embarrassing public elimination of bodily wastes, societal standards are being affronted by these inappropriate behaviours (Keltner et al 2003:9). Accommodation for the mentally ill persons should be of such a nature that they have the opportunity to be kept busy and to keep in social contact with people in their community to develop new interests (Uys & Middleton 2010:426).

MHCUs were discharged into the community in the hope, that good living conditions provided by the family and psychiatric treatment provided in community centers, would allow them to live in harmony with others. However, it was not the case, as some of the patients had to be re-admitted to state hospitals because they could not be cared for in the community. Mentally ill patients who could not meet the admission criteria of hospitalisation drifted into the criminal justice system or into homelessness (Stuart 2009:629).

Stuart (2009:629) states that the following problems can and do result in the failure of community care:

- Poor coordination between hospitals and community mental health centres.
- Underestimation of the support systems needed to enable mentally ill people to live in the community.
- Lack of knowledge about mental illness and rehabilitation.
- Underestimation of community resistance to deinstitutionalisation.

2.5 FAMILIES LIVING WITH MENTAL ILLNESS

A family is important for the treatment and rehabilitation of the mentally ill patients, and their inclusion in the treatment process greatly decreases the relapse of the mentally ill patients (Uys & Middleton 2010:95). When a loved one is stricken with mental illness, every member of the family feels pain as well as other feelings that confuse and frighten them (Stuart 2009:146). Family members can help by identifying potential problem areas and may enhance the patient's adherence to the treatment plan. Unfortunately family members are often overlooked by the health professionals and not provided with education about the mental illness (Stuart 2009:204).

There are two types of families, namely those with high expressed emotion and those with low expressed emotion (Uys & Middleton 2010:431). The members of families with high expressed emotions are usually verbally and non-verbally critical in their communication with patients. They do not believe that the patients are ill and expect them to take responsibility for their conduct and circumstances, but at the same time they are overprotective of the patients. Mentally ill patients are not allowed to make decisions and carry out activities on their own. The rehabilitation of a mentally ill patient placed with this type of family appears to be very poor (Uys & Middleton 2010:431).

Members of families with low expressed emotion believe that mental illness is caused by factors beyond the control of the patient. They allow the patient social freedom and to take responsibility for their own decisions and health. These families appear to be neglecting the mentally ill patient, but schizophrenic patients discharged to them do very well (Uys & Middleton 2010:431).

The impact of the news of mental illness is a shattering, traumatic event in the life of a family and, as such, family members are the ideal candidates for secondary prevention strategies (Stuart 2009:147). For many years families of patients with mental illness were considered to be part of the problem and , not part of the solution, although the families have been involved in the care of patients with different diseases (Stuart 2009:141). A well-functioning family can shift roles, levels of responsibility and patterns of interaction as they experience stressful life changes (Stuart 2009:142).

Families that are intimately involved with the mentally ill members and are affected by the illness, also shoulder the greatest part of the burden of caring for patients. The family remains the main resource and support system of the person suffering from mental illness. Families act as the main caregivers, they support other families with similar problems, and they teach and educate other consumers and the public at large. They participate in research and advocate improved services both for the patient and for others in the community (Uys & Middleton 2010:88).

2.5.1 The meaning of mental illness to the family

When a loved one is mentally ill, every member of the family feels and suffers pain, whether the person is a mother, father, son, daughter or grandchild, as they share in the suffering. Before the diagnosis, family members often go through a period of uncertainty, trying to make sense of what is happening (Stuart 2009:146).

The way in which people deal with something depends on how they understand and explain it. In 1994, Solombela and Uys cited in Uys and Middleton (2010:90) revealed that relapsed patients with schizophrenia and their families apparently believed in witchcraft and evil spirits.

Uys and Middleton (2010:90) refer to the following models of families distinguished in a sample in the USA:

- *Strong biological model.* These families see mental illness as a brain disorder. This belief leads the families to concentrate on the following coping behaviours: using medicine, nutrition, rest and exercise.

- *Rational control model.* These families believe that if patients can be influenced to think differently, they can act differently. The family attempt to cure the mental illness by argument and persuasion.
- *Normalising model.* These families believe that symptoms can be reduced by identifying those circumstances which cause negative symptoms, and by creating an environment that stimulates positive responses.
- *Survival through symptoms model.* These families interpret all symptoms as coping strategies which the mentally ill person uses to deal with the pain and confusion caused by the malfunctioning brain. Families with these beliefs express great personal distress about the patient's condition. Uys and Middleton (2010:91) point out that the belief system may assist in the treatment and rehabilitation of mentally ill patients, although it may not be totally relevant to South African families.

2.5.2 Needs of mentally ill patients

Mentally ill patients have the same needs as other individuals, namely physiological needs, safety, love and belonging, esteem and recognition, and self-actualisation (Kneisl & Trigoboff 2009:77). According to Maslow's hierarchy of needs, an individual's behaviour is motivated by universal needs that range from the most basic to the highest needs (see figure 2.1).

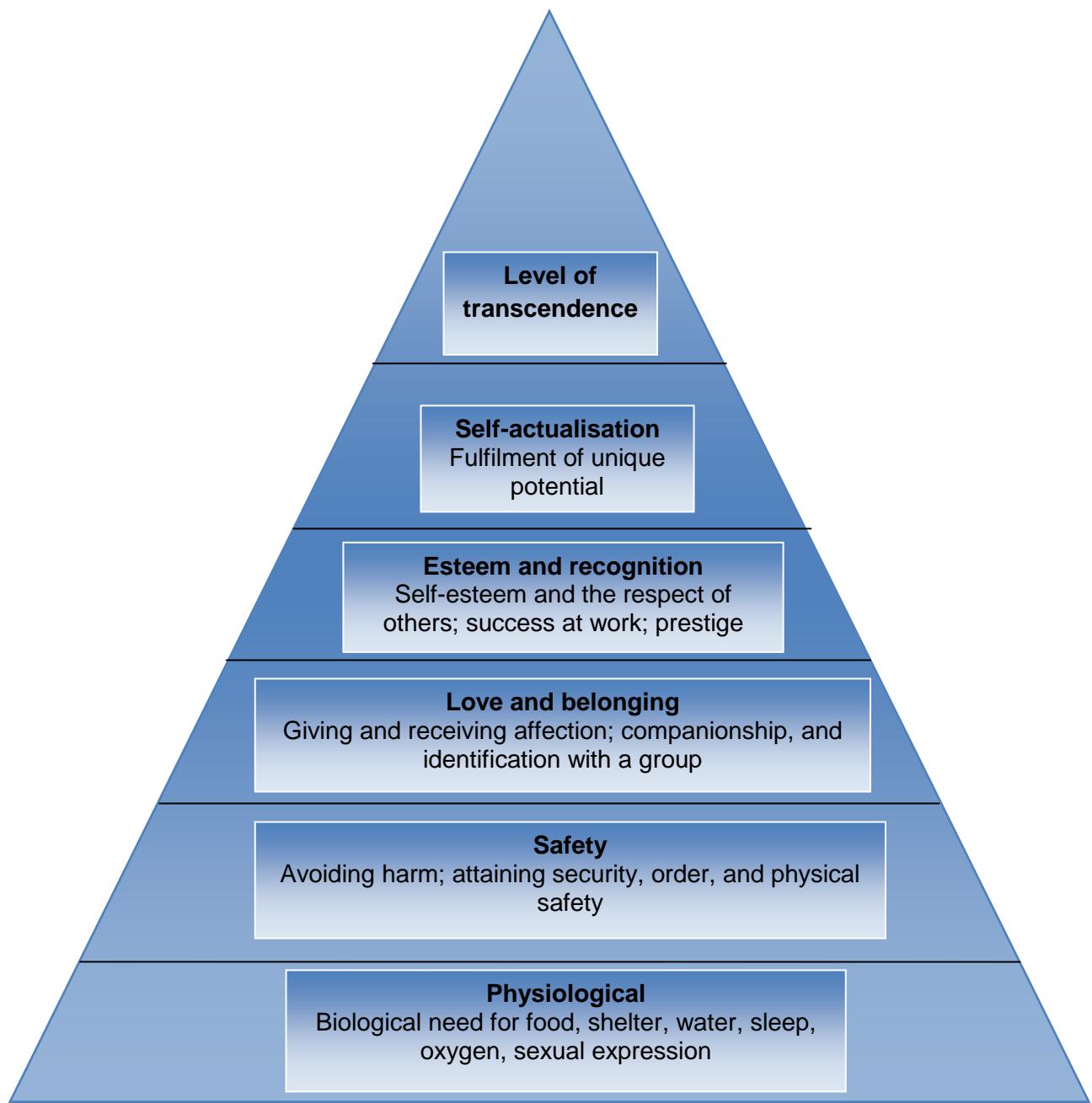


Figure 2.1 Maslow's hierarchy of needs

(Adapted from Kneisl & Trigoboff 2009:77)

The six levels in Maslow's hierarchy of needs are as follows (Kneisl & Trigoboff 2009:77):

- *Physiological needs.* These represent the most basic level in the hierarchy and comprise of food, shelter, water, sleep and sexual expression needs. As long as these needs are unsatisfied, mentally ill patients will strive to satisfy them, although it might be by means of aggressive behaviour. However, once these needs are satisfied, they may no longer influence behaviour.
- *Safety needs.* Once a patient's basic physiological needs have been satisfied, the safety needs arise. Stuart (2009:355) posits that patient safety is the most important issue during the crisis and acute phases, particularly since 9% to 13% of patients with schizophrenia commit suicide, and 20% to 40% attempt suicide. Patients may accidentally harm themselves because of impaired judgment or as a response to hallucinations or delusions. Helping the patients reduce anxiety and feel safe and accepted decreases the incidence of harmful behaviours towards the self and others (Stuart 2009:355).
- *Love and belonging.* Mentally ill patients have the right to develop intimacy with peers of the same sex and later of the opposite sex. In terms of the *Mental Health Care Act, 17 of 2002* (South Africa 2002:20) intimate relationships of an adult MHCU may be limited only if due to mental illness, the ability of the user to consent is diminished. The failure to satisfy the needs for love and belonging may lead to feelings of helplessness, hopelessness and worthlessness until the stage where the patient resorts to destructive behaviour.
- *Esteem and recognition.* One of the higher order needs is the need for self respect and recognition by others. The *Mental Health Care Act, 17 of 2002* (South Africa 2002:16) stipulates that the person, human dignity and privacy of every MHCU must be respected, and they must be provided with care, treatment and rehabilitation services to improve their mental capacity and feelings of worth. Mentally ill patients are often stigmatised. Firstly, the individual is marked out as different by their actions or appearance as observed by others. Secondly, society develops a series of beliefs about the mentally ill individual and finally society changes its behaviour towards the individual, in a way that is consistent with the developed beliefs. This attitude can be associated with avoidance of the stigmatised individual (Semple & Symth 2009:18).

- *Self-actualisation.* This category represents the apex of human needs. Mentally ill patients may be helped by creating a climate in which self-actualisation is possible; for example, by providing them with skills development, and giving them the chance to be creative.
- *Level of transcendence.* This category of needs deals with the spiritual needs. Even people who have no religious faith or are not members of an organised religion have belief systems that give their lives meaning and purpose. Patients often report unmet spiritual needs, and spiritual support which is associated with a better quality of life, although there are barriers in the health care system that makes it difficult to address these needs (Bussing & Koenig 2010:18).

2.5.3 Family caregivers

Caregivers may be defined in many different ways depending on their relationship to the care recipient. They may live together with the care recipient or may live separately. Stuart (2009:141) defines family caregivers as those who by birth, adoption, marriage or declared commitment share deep personal connections and are mutually entitled to receive and are obligated to provide support to a patient, especially in times of need. Family caregivers are the people who provide care for partners, parents, children, brothers, sisters and cousins when everyone else has gone. The families and the other caregivers can be a major source of support for individuals who have serious mental illnesses (Stuart 2009:204).

Family caregivers generally support the independence of the individual with mental illness. They play a critical role in the health and long-term care system by providing care for a mentally ill member. When caregivers set aside their own needs and sacrifice themselves for their relatives to assume caregiver's responsibilities they are at high risk for caregiver burden, physical and mental illnesses, financial burden, social isolation and depressive symptoms (Wetters 2010:1).

Caring is an interpersonal process that connects those who care and those who are cared for. Caring for a family member with chronic mental illness is a lived experience that is embodied both personally and in the fabric of family relationships. The phenomenon of family caring is one of relationality, of living in relation to the other. The relationship of the carer to the family member with chronic mental illness is only one

part of the experience. Most of the responsibility for caring, whether for the elderly or physically or mentally ill family member, falls on the female kin, most often mothers and daughters (Jeon & Madjar 1998:694). When couples share the responsibilities of caring for their children, marital relationships are commonly affected. For instance, conflicts often occur due to disagreements related to the provision of the best possible care for the mentally ill family member. Family caregivers feel it is important and natural to consider the ill relative's needs before anyone else's. Caring by family members is different from the care provided by health professionals or others because caring in this sense goes beyond helping and looking after someone in need (Jeon & Madjar 1998:694).

Jeon and Madjar (1998:695) identify different styles of interaction and care giving, namely engaged, conflicted, managed and distanced care. In engaged care, parents continue to care for their children and to show an understanding and acceptance of their difficult and inappropriate behaviours. In conflicted care, parents show little understanding or acceptance of their children's illness and behaviour and try to minimise any impact on their own lives, as continued provision of care results in conflict and extreme dissatisfaction with their life situation. In managed care parents are eagerly active and objective in managing and learning to cope, yet they find the experience very draining and express a strong need for breaks from the work of caring. Distanced care is evident mostly in fathers who entrusted the direct care-giving work to another member of the family, most often their wives and they report feeling emotionally hurt and excluded from giving care (Jeon & Madjar 1998:695).

2.5.3.1 *Caregiver burden*

The mental illness of a family member affects the entire family. Most burdens are related to worry about the future, poor concentration, upset household routine, feeling guilty about not doing enough, feeling trapped, and being upset by changes in their family member (Stuart 2009:205).

The burden may be objective or subjective. *Objective burden* is related to the patient's behaviour, role performance, adverse effects on the family, need for support, and financial cost of the illness. It also involves the amount of energy and time spent

performing tasks that may be unfamiliar, unpleasant and uncomfortable. Finkelman (2000:143) identifies the following objective burdens:

- Financial challenges resulting from the cost of treatment. Family members may need to take time off from work and thus suffer financial losses. If the mentally ill member was the main provider, the family may experience major financial constraints.
- Role changes, either temporary or permanent. Parents who thought their children were adults now must resume the parent / child role or a wife may need to take over the ill husband's responsibilities. Adult children may find that they have to be the "parent" to a mentally ill mother. Role changes mean additional responsibilities and stress for the family.
- Inadequate resources for support and treatment become evident as the family may struggle to find appropriate resources.
- Disruption in personal lives. Flexibility becomes critical, and this demand increases disruption in personal activities, social lives and employment of family members (Finkelman 2000:143).

Subjective burden is the person's own feeling of being burdened. It is individual and not consistently related to the elements of objective burden. It involves how the caregivers feel about their roles. They may have feelings of role captivity and role strains. Role captivity occurs when caregivers feel trapped in a family member's illness with regard to years of caring and type of tasks involved in caring, whereas role strain refers to secondary stressors that caregivers face, such as disagreements, with other family members about the care or neglecting other relationships and tasks because of the time consuming nature of care giving (Wetters 2010:2).

Caregiver burden may be experienced differently by each person, depending on how the caregiver copes with the demands of care. Caregivers who have higher levels of stress report poorer health and physical functioning, and increased depressed symptoms and moodiness, and are less likely to practise self care (Wetters 2010:2).

Finkelman (2000:143) identifies anxiety, depression, grief, and physical health problems as subjective burdens.

2.5.3.2 Caregiver depressive symptoms

A major negative consequence of caregiver burden is depression. The negative effects on caregivers do not stop at health concerns but younger caregivers also experience disruption in their education, putting school on hold or dropping out entirely which can impact their future career and earnings (Wetters 2010:2).

2.5.3.3 Factors contributing to caregiver burden

Most caregivers do not receive formal training in caring for patients and lack the support needed to assume full-time care-giving responsibility. They are also required to relinquish their own needs to meet the needs of the family member and this can further increase the caregivers' burden. Some caregivers may not seek assistance or have support from other sources. The reasons for the underutilisation of the formal service include caregiver guilt, the lack of trust in staff caring for a loved one, worry that the loved one may become upset or confused, limited finances, and lack of support to access these services (Wetters 2010:3).

2.5.3.4 Unmet needs of caregivers

The main unmet need is obtaining medical help for the mentally ill family member and managing stress. Many caregivers have difficulty finding information and support groups to teach them how to manage and provide care to a mentally ill patient. They need friends, family members, health care providers or neighbours who can listen, provide empathy, and offer emotional support to them (Wetters 2010:3).

2.5.4 Responses of family members to mental illness

Finkelman (2000:144) and Stuart (2009:205) identify the following responses in families with members with serious mental illness:

- **Grief** is common and is related to the loss of the person they knew before the illness as well as the loss of the future that they expected to share with the mentally ill family member. Finkelman (2000:144) states that as families grieve

they go through stages. In the first stage, of **avoidance**, the family experiences shock, disorientation, sleeplessness, poor memory, unpredictable mood swings and denial. During the **confrontation phase**, the family tries to understand the illness and treatment needs and the varied way in which the individual family member responds. During the **reestablishment phase**, some level of equilibrium is established, but the nature of the illness means that stability may change quickly.

- **Guilt** is common to those who are close to a person with any serious illness to constantly think whether they could have done something to prevent it.
- **Anger** may be directed towards the patient, but it is more often felt toward other family members, mental health care providers or the entire health care system. Anger within the family relates to differing perceptions of the patient and ideas about how to manage the illness.
- **Powerlessness and fear** often results from families' realisation that they are dealing with a long-term recurrent illness. Most individuals believe that the health care system should cure illnesses, and when this is impossible they feel powerless and frustrated. This understanding can result in fear about the future of the mentally ill family member as well as fear for themselves. Some families fear that the mentally ill family member may become dangerous if they stop adhering to their treatment (Stuart 2009:205).

Family members providing care for members who have serious mental illness often feel isolated and alone in dealing with the challenges of care giving. They may be embarrassed about the illness or fear that the person with mental illness will behave inappropriately in the presence of others. Some family members may decide to stop working outside the home to be more available for the mentally ill relative (Stuart 2009:205).

Most families of mentally ill patients report that caring for the ill member is a very important, largely underappreciated , stigmatised and expensive lifelong task (Kneisl & Trigoboff 2009:820). Families are sometimes compelled to provide support to the mentally ill relative, even if they are not physically well. Mentally ill patients should also be helped to develop strength and potential, establish goals , set priorities for skill development, learn living skills, manage their illnesses and access environmental support (Stuart 2009:204).

2.5.5 Benefits of family involvement

There are many benefits to involving families in their care of the mentally ill relatives. Family input in treatment decisions improves patient outcomes with maximum benefits occurring when the families are educated on their caregiving roles (Stuart 2009:145).

In China, there is close involvement of families in the care of the mentally ill relative because taking care of one's own family is a natural responsibility in the culture (Kung 2003:548). Although care giving can lead to psychological, physical and material burden, some families feel happier and closer to the mentally ill family member. Family members caring for mentally ill patients are regarded as experts in the field of caring because of the experiences that they have obtained and been exposed to. A person with considerable experience in a certain field can gain a reputation as an expert.

Benefits of family involvement are listed as follows:

- **Gaining information and practical knowledge.** Through support groups and other service programmes, families gather practical knowledge, develop new skills and learn about resources. Information on mental illness is also learned. Families also discover that they become more positive in their care-giving roles when they receive support from other carers (Mohammad et al 2011:1).
- **Utilising free time.** Caregivers are able to recognise specific personal problems or emotions that prevent them from enjoying their care giving role. Families manage to identify specific personal gains such as having more time for themselves, having some freedom, feeling relief and rest, and being able to go away and relax. Carers also found that it is important to have a temporary place to place the mentally ill relative so that they can enjoy their social life. Mentally ill patients should also be taught certain skills to use after discharge, such as leather work and sports activities (Uys & Middleton 2010:436).
- **Companionship.** Patients with long term psychotic disorders lack certain skills and this is a limiting factor in their rehabilitation. They have difficulty initiating conversations and may be incapable of forming and maintaining friendships (Uys & Middleton 2010:430). However, some of the carers found that care giving helps to stimulate and provide companionship for the mentally ill relative.

2.5.6 Barriers to family involvement

Stuart (2009:145) points out the following barriers to educating families on their involvement in their loved one's treatment:

- Professional bias against families based on exposure to family systems theories suggest that families cause or perpetuate the illnesses.
- Family attitudes that equate all family interventions with past, unwelcome experiences with family therapy.
- Professional fears that an alliance with the family will endanger confidentiality and threaten the therapeutic alliance with the patient.
- Administrative restraints in a cost managed environment, where services to the families receive the lowest priority.

2.5.7 Families and health care professionals

In a study to assess family attitudes towards the staff, Finkelman (2000:143) identified the following:

- Families perceived that the staff blamed them for the onset of the illness.
- Staff lacked empathy for stressors and disappointments that the family experienced.
- Respect for family efforts was lacking.
- Inadequate information was provided about the mental illness and treatment.
- Emotional support was insufficient.

Health care professionals need to be aware of the identified experiences by family members, as this may affect the family's response to care of their mentally ill relatives.

2.5.7.1 Family assessments

Stuart (2009:205) identifies the components of family assessments whereby the nurse who assesses the family as part of the rehabilitation plan should consider the following aspects of family dynamics:

- Family structure, including developmental stage, roles, responsibilities, norms and values.
- Family attitudes towards the mentally ill member.
- The family's emotional climate.
- The social supports available to the family, including extended family, friends, financial support, religious involvement, and community contacts.
- The past family experiences with mental health services
- The family's understanding of the patient's problems and the plan of care.

According to Finkelman (2000:145), health professionals should undertake family assessments prior to the discharge of the mentally ill into the community. A discussion with the family to clarify mutual goals that are reasonable and achievable would help to improve the self-esteem and the need for the family to feel in control.

2.6 CHALLENGES OF MENTAL ILLNESS TO THE FAMILY

Caring for a family member suffering from a long-term mental illness such as schizophrenia is an enormous burden (Kung 2003:547). Two major challenges are social stigma and unemployment.

2.6.1 Social stigma

Uys and Middleton (2010:85) state that the word “stigma” comes from the mark branded on a slave and refers to an imputation which stains or scars a person’s reputation. In other words, it is something that brands a person in a negative way in the eyes of society. Semple and Smyth (2009:18) state that “stigma” is a Greek word meaning “mark” and originally referred to a sign branded on criminals or traitors in order to identify them publicly. In a modern sense, stigma refers to the sense of collective disapproval and group of negative perceptions attached to particular people, such as mentally ill people.

Stigma against mentally ill patients is common in SA. In a small pilot study in a township outside Durban, participants indicated that they would not like to live in the same block of flats with a mentally ill person or have a mentally ill person as a neighbour (Uys &

Middleton 2010:85). South African “medical aid companies and state-funded health systems also discriminate against mentally ill patients by not paying for their hospitalisation resulting from suicide attempts or covering hospitalisation due to mental illness with a low cover” (Uys & Middleton 2010:85).

The stigma attached to mental illness and the practical strains involved in caring for a patient are significant sources of stress. Minority families with a mentally ill relative experience double stigma: from both the illness and their minority status (Kung 2003:547). Some families prefer that the mentally ill patient be admitted to an institution, rather than receive care at home, to avoid social stigma. The generalisation of stigma to families is an additional source of psychological risk for both the mentally ill patients and the family members (Mohammad et al 2011:1).

Specific types of barriers may affect the coping capacities of the patient’s relatives and the staying powers of a needed support. Stigma is a source of burden to caregivers, it increases the subjective burden, it lowers access to social support, resources and opportunities like finding work and housing, and also leads to social isolation (Kung 2003:548).

For the mentally ill persons, stigma is a barrier that separates them from society and keeps them apart from others (Stuart 2009:179). Stigma is attributed to public beliefs about parental roles in causing the disorder, and often results in disrupted family relationships with other family members as well as with the mentally ill relatives. Even among those who have finally accepted that they did not cause the mental illness, they have residual guilt for the failure to recognise symptoms and to seek help early (Uys & Middleton 2010:85). All these perceptions are based on a lack about knowledge and understanding of mental illness and its treatment.

2.6.2 Unemployment

The rate of persons with mental illness being employed is generally low because of the stigma attached, although the *Employment Equity Act, 55 of 1998* (South Africa 1998:12) makes provision for achieving equity in the workplace by promoting equal opportunity and fair treatment in employment through the elimination of unfair

discrimination. Once their mental status is revealed at work, they are rejected or treated as incompetent by the employers regardless of the skills that they possess.

Schizophrenic patients who work are hospitalised less frequently than those who do not work. Employment may contribute to more effective functioning. Access to meaningful, paid work is a basic human right for every citizen, and those who experience serious mental illness should have equal access to the fundamental elements of citizenship, including work and income. Most schizophrenic patients have a poor work record due to the lack of drive, limited interpersonal and social relationships, the lack of job experience and the almost complete lack of job specialisation (Uys & Middleton 2010:435).

Employment enables social inclusion and represents an important way in which people with mental illness can meaningfully participate in society. It further reduces the burden on families and carers. Through disruptions in education, mental illness can indirectly cause long-term unemployment and may limit career prospects for the individual. Career paths can be displaced downwards and may limit the attainment to less skilled jobs, thereby lowering work status and income expectations for the mentally ill persons.

Stuart (2009:211) found that when asked about their vision of recovery, most individuals with serious mental illness identified employment as a major focus. Stuart (2009:211) adds that there are a number of barriers to employment for mentally ill patients but the following actions would help to overcome them:

- Ongoing health insurance for medical care, mental health care and medications regardless of employment status.
- Access to educational programmes.
- Legal aid to deal with discrimination.
- Peer support and self-help.

Waghorn and Lloyd (2005:16) found that one participant indicated that employment had taken away the dread of socialising and meeting new people. Mentally ill patients experienced the embarrassment of saying that they were unemployed or that they received a disability grant. However, not every person with more severe forms of mental

illness such as schizophrenia who attempt employment, experience reduced clinical symptoms.

2.7 CONCEPTUAL MODEL

According to Burns and Grove (2009:135), a conceptual model is a set of highly abstract, related constructs. It explains the phenomena of interest, expresses the assumptions and reflects a philosophical stance. The model identifies the constructs which are considered to be essential to adaptation and how the constructs interact to produce adaptation. Polit and Beck (2008:141) state that a conceptual model deals with abstractions that are assembled by virtue of their relevance to a common theme. Conceptual models provide a perspective depicting the interrelated phenomena graphically. The map summarises and integrates what is known about the phenomenon. All the major concepts are included in boxes, symbols and are linked by arrows to express the linkages between the concepts (Polit & Beck 2008:141).

In this study the researcher used the health care systems conceptual model to guide the data collection and the analysis process. The study sought to identify and map out the patterns of experiences of family members who care for a long-term mentally ill patient.

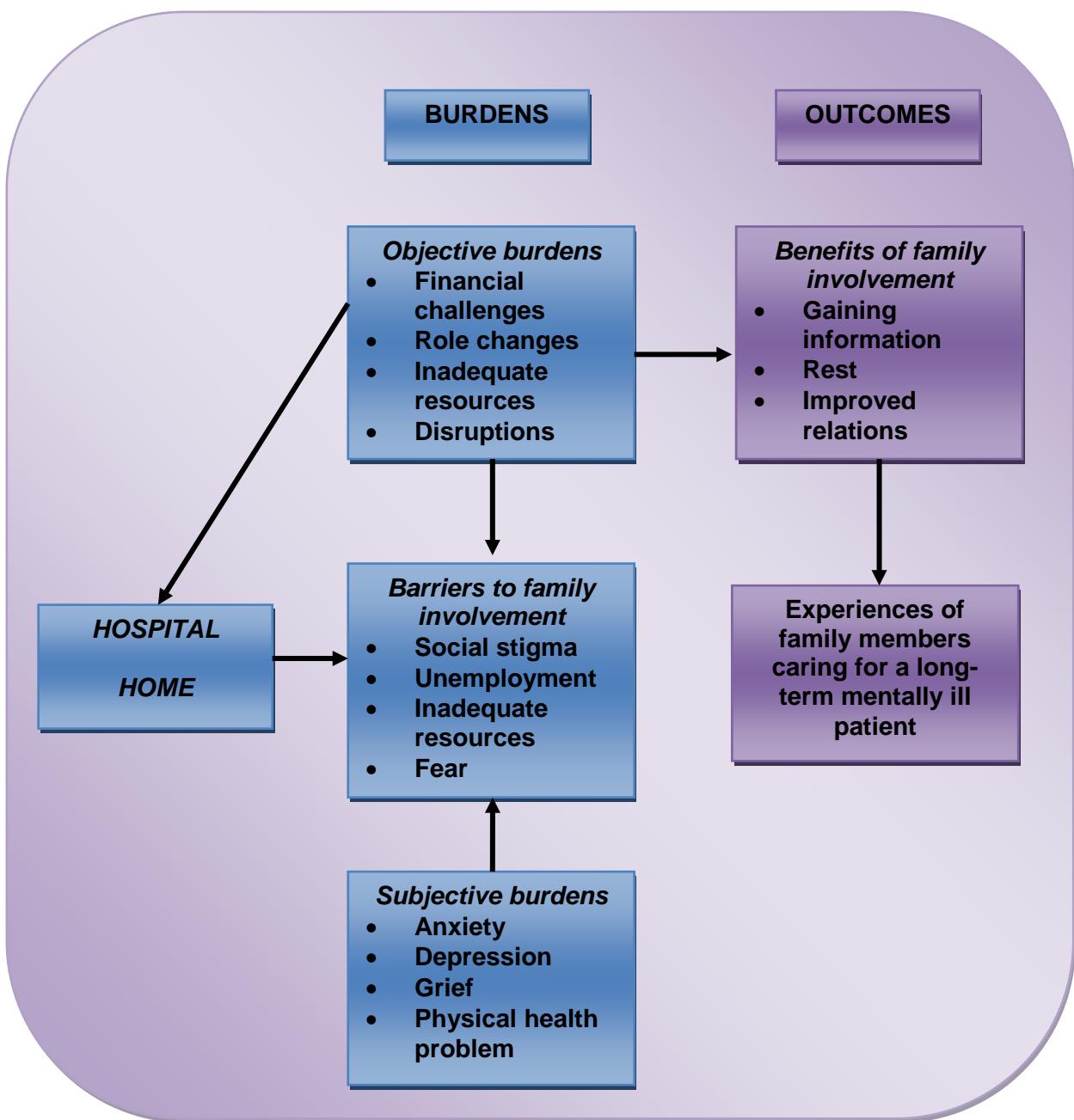


Figure 2.2 The health care systems conceptual model

(Adapted from Stanhope & Lancaster 2000:209)

Figure 2.2 indicates that the *objective burdens* faced by the family include financial challenges, role changes, inadequate resources, and disruption in their personal lives. Long-term mental illness means arrangements will change in the family. If the mentally ill patient is the main provider, the family may suffer major financial constraints which may lead to inadequate resources. Other family members will seek employment to take the role of providing for the family, leading to role changes. Therefore, the mentally ill

patients may be left alone at home, in the care of children or distant relatives. The lives of family members may be disrupted in terms of domestic routine, social and leisure activities.

The *subjective burdens* include anxiety, depression, grief and physical health problems. Mental illness is a crisis for the family and coping with it varies among families, although all families experience grief as a result of the loss of the person they knew prior to the mental illness. Caregivers have to deal with the demands and stresses related to the care of their mentally ill relatives, but also had to struggle with the rest of the family members who also need attention and care. The competing demands and the work involved in caring for the long term mentally ill patient may lead to depression and deterioration in physical health.

Figure 2.2 indicates that the *benefits of family involvement* include gaining information, rest, and improved relations. The involvement of family members in community support groups results in reducing feelings of isolation and grief and in gaining more knowledge about the mental illness. Family members through the knowledge and support received are able to make short- and long-term plans to make time to rest.

At the same time, the *barriers to family involvement* include stigma, unemployment, inadequate resources, and fear. Stigma attached to mental illness is a significant source of stress to the family as it lowers access to opportunities and leads to social isolation in order to conceal the illness. Families avoid being seen with the mentally ill patient to avoid embarrassment over the mentally ill patient's unpredictable behaviour. Due to the stigma of mental illness, unemployment may result to both the mentally ill patient and to the family members. The family members' physical health problems and the competing demands of work and at home may lead to absenteeism and dismissal at work. The mentally ill patient may also be dismissed from work due to stigma.

2.8 CONCLUSION

This chapter discussed the literature review conducted on the various aspects of mental illness and the family.

Chapter 3 describes the research design and methodology of this study.

CHAPTER 3

Research design and methodology

3.1 INTRODUCTION

This chapter describes the research design and methodology of the study, including the setting, population, sample, data collection and analysis, methods to ensure trustworthiness, and ethical considerations.

3.2 RESEARCH SETTING

Letaba Hospital is a provincial psychiatric hospital in the Limpopo Province, South Africa, which oversees six district hospitals, namely Sekororo, Maphuta Malatjie, Evuxakeni, Dr CN Phatudi, Nkhensani and Van Velden Hospitals including clinics and villages catered for by these hospitals. Letaba Hospital is designated to admit mentally ill patients for short- and long-term care. It has one psychiatrist, three medical practitioners, ten professional psychiatric nurses, five enrolled nurses and twenty five enrolled nursing auxiliaries (see chapter 1, table 1.1). The most common mental illnesses treated at the Letaba Hospital are schizophrenia, psychosis, bipolar mood disorders and substance abuse (see chapter 1, tables 1.2 and 1.3).

In this study, clinical observation of the behaviour of relatives when they brought mentally ill patients to the hospital, and questioning and interviewing during history taking led the researcher to question what interventions could be used to improve the family's coping skills. Accordingly, the researcher wished to study a family living with and caring for a long-term mentally ill patient. The family caring for a long-term mentally ill patient was identified from the Letaba Hospital records.

A setting is the location where a study is conducted (Burns & Grove 2009:35). This study was conducted in a natural or real-life setting, namely the home setting of a family of a long-term mentally ill patient treated in the Mopani District in Tzaneen in the Limpopo Province.



Figure 3.1 Area map of the research site

(<http://maps.Letaba hospital.google.com>)

The home is the natural setting for the patients as it is here where they deal with everyday problems and truly interact with the family and with others. Helping the family cope with problems of this nature in this environment is usually more effective because they have a better understanding of the effects of the illness on the patient and family life.

3.3 RESEARCH DESIGN

A research design is the set of logical steps taken by the researcher to answer the research question (Brink et al 2008:92). A research design is an overall plan for obtaining answers to the research questions (Polit & Beck 2008:66). According to Burns and Grove (2009:236), a research design is the blueprint for conducting a study that maximises control over factors that could interfere with the credibility of the findings and ensures greater control and improves the trustworthiness of the study. The researcher used a qualitative, explorative and descriptive design in this study.

3.3.1 Qualitative

Qualitative research is a systematic, interactive, subjective approach used to describe people's life experiences and to give meaning to them. It is conducted to describe and promote understanding of human experiences such as pain, caring and comfort (Burns & Grove 2009:22). Creswell (2007:249) describes qualitative research as "a process of inquiry of understanding human experiences based on a distinct methodological tradition that explores a social or human problem". Qualitative research involves viewing characteristics or qualities that cannot easily be reduced to numerical values (Leedy & Ormrod 2010:94).

It is a way of gaining insight through discovering meanings. In qualitative studies, researchers begin by talking with or observing people who have had first-hand experience of the phenomenon under study (Polit & Beck 2008:17). This approach results in obtaining information that has the potential to explain the varied dimensions of complicated phenomena, including caring for a long-term mentally ill patient. The researcher selected a qualitative design in order to investigate the experiences of family members caring for a long-term mentally ill patient.

In this study, a qualitative approach had the following advantages:

- Qualitative methods are useful for exploring the full nature of a phenomenon that is less understood (Polit & Beck 2008:20).
- Qualitative methods enable researchers to search for explanations about how or why a phenomenon that is less understood exists or what a phenomenon means as a basis for developing a theory that is grounded in rich, in-depth, experiential and empirical evidence. This mode of enquiry aims to examine the nuances and complexities of a particular phenomenon (Leedy & Ormrod 2010:94).
- The type of data obtained and the people selected as participants become focused and purposeful as the conceptualisation is developed and refined (Polit & Beck 2008:70). The focus of qualitative research is usually broad and the intent is to give meaning to the whole with the qualitative researcher having an active part in the study (Burns & Grove 2009:23).

- The participants who participated in the study were knowledgeable informants on the subject of caring for a schizophrenic patient.

This approach assisted the researcher to construct representations based on the family members' detailed knowledge and experiences of care for a long-term mentally ill patient (Polit & Beck 2008:70). Furthermore, the design was suitable for gaining insight into the experiences of family members who care for a long-term mentally ill patient and that reality that they attached to their world.

3.3.2 Explorative

Explorative research investigates “the full nature of a phenomenon, the manner in which it is manifested and other related factors” (Polit & Beck 2008:20). Explorative research begins with a phenomenon of interest and explores the full nature of that phenomenon (Polit & Beck 2008:20-21). This design was used to obtain basic information about the experiences the family members had when caring for a schizophrenic patient (Fouche & De Vos in De Vos et al 2005:106). LoBiondo-Wood and Haber (2010:198) state that research is exploratory when the researcher “searches for accurate information about the characteristics of particular subjects, groups, institutions or about the frequency of a phenomenon’s occurrence, particularly when little is known about the phenomenon”. An exploratory design was selected as the researcher intended to assess and understand the experiences of families in a new light, ask questions during the in-depth interviews, and search for new insights (Polit & Beck 2008:21).

Researchers in exploratory studies should be creative, open minded, flexible and explore all sources of information to gather new data (Neuman 2006:34). However, exploratory designs are not intended for generalisation to large populations, they are designed to increase knowledge of the field of study (Burns & Grove 2009:359). Neuman (2006:34) adds that exploratory studies often go unpublished, although they may be incorporated into a more systemic research that is published later.

3.3.3 Descriptive

The purpose of descriptive research is to “describe phenomena in real-life situations. Through descriptive research, concepts are described and relationships identified

through" (Burns & Grove 2009:45). Descriptive designs are commonly used in nursing research and are crafted to gain more information about the characteristics of the phenomenon being studied. Their purpose is to provide a picture of situations as they naturally occur (Brink et al 2008:102; Burns & Grove 2009:237; Polit & Beck 2008:274). Neuman (2006:35) states that the primary purpose in descriptive research is to paint a picture using words or numbers and to present a profile, a classification of types or an outline of steps to answer questions such as who, when, where and how of the research study?

3.4 RESEARCH METHODOLOGY

Research methodology refers to the logical process followed during the application of scientific methods and techniques when a particular phenomenon is investigated (Polit & Beck 2008:765).

3.4.1 Population

According to Burns and Grove (2009:42), a research population refers to all the elements, individuals, objects or substances that meet certain criteria for inclusion in a given universe. A population is a collection of objects, events or individuals having some common characteristics that the researcher is interested in studying (Brink et al 2008:206; Neuman 2006:224; Polit & Beck 2008:67). The target population included all the families in the hospital records that provided care to a long-term mentally ill patient. The accessible population for this study was the family caring for a long-term patient suffering from schizophrenia (Burns & Grove 2009:343; Polit & Beck 2008:767).

Inclusion criteria refer to those characteristics that a subject must possess to be part of the target population (Burns & Grove 2009:345; Polit & Beck 2008:338). To be included in this study, the participants were male or female family members of the affected patient, between 10 and 60 years of age, and able to speak Tsonga, Northern Sotho or English. The patient involved was diagnosed with a long-term mental illness and cared for by the family members for over two years. In addition, the patient was admitted and discharged intermittently at the same hospital for over two years.

3.4.2 Sampling and sample

Sampling means taking any portion of a population or universe as representative of that population or universe (Burns & Grove 2009:35; Polit & Beck 2008:339; Strydom in De Vos et al 2005:193). Qualitative research involves non-probability sampling. Generalisability of the research findings is not the guiding criterion even though the rigor of the methodologies can be replicated in similar settings. In qualitative studies, researchers are not concerned with the selection of representative samples. Samples are small and non-randomly selected. In non-probability sampling, the sample is not necessarily representative of the population and the findings cannot be generalised to the population. The elements are selected based on their contribution to the data required (Burns & Grove 2009:353; Polit & Beck 2008:759). Small information-rich samples have the benefit of allowing qualitative researchers to conduct in-depth investigations and to generate rich data which is required to discover inherent meanings (Burns & Grove 2009:361).

The researcher used non-probability and purposive sampling to select participants who had the relevant knowledge of caring for a long-term mentally ill patient (Burns & Grove 2009:355). Purposive sampling involves selecting participants that will most benefit the study.

A sample is part of a fraction of a whole, or a subset of a larger set, selected by the researcher to participate in a research study (Brink et al 2008:124; Burns & Grove 2009:42; Polit & Beck 2008:339). Strydom in De Vos et al (2005:194) describes a sample as a small portion of the total set of objects, events or persons which together comprise the subject of the study. A critical step in qualitative studies is selecting a sample with high potential for information richness.

In qualitative studies , sample size is determined on informational needs and the guiding principle is data saturation; that is, sampling to the point at which no new information is obtained and redundancy is achieved (Burns & Grove 2009:361; Polit & Beck 2008:357). The important factors that must be considered in determining sample size to achieve saturation of data are the scope of the study, nature of the topic, quality of data, and the study design (Burns & Grove 2009:361; Polit & Beck 2008:357).

In this study a sample of one family caring for a long-term mentally ill patient was identified from the hospital records and selected for unstructured interviews.

3.4.3 Case study

The researcher conducted a case study of the family selected, as case studies involve intensive investigation of a social entity. The purpose was to describe the case being studied, namely the experiences of a family caring for a patient with schizophrenia. A case study involves an intensive exploration of a single unit of study, such as a person, family, group, community or an institution or a small number of subjects who are examined intensively (Brink et al 2008:110; Burns & Grove 2009:244). Case studies are chosen so that comparisons can be made between cases and concepts and so that theories can be extended and validated (Fouche in De Vos et al 2005:272).

The researcher undertook an intrinsic or instrumental case study with the intention of gaining a better understanding of the individual case and deeper insight into the experiences of family members caring for a long-term mentally ill patient.

A case study also explains the causes of the phenomenon or event in addition to describing it, which helps researchers to study the why and what of phenomena (Brink et al 2008:110). Furthermore, it is a suitable method for learning more about a poorly understood situation and is useful for investigating how an individual or programme changes over time, perhaps as the result of certain circumstances or interventions (Leedy & Ormrod 2010:137).

The limitation of a case study, however, is when a single case is involved as the findings cannot be generalised to other situations (Leedy & Ormrod 2010:137; Polit & Beck 2008:236).

3.4.4 Data collection

Data collection is “the precise, systematic gathering of information relevant to the research purpose or specific objectives, questions or hypothesis of a study” (Burns & Grove 2009:43). Data refers to numerical and non-numerical information and evidence carefully gathered according to rules or established procedures (Neuman 2006:8).

Qualitative research uses several data-collection methods, such as observation, interviews, written documents and records. In this study, the researcher used individual in-depth interviews, direct observation and field notes to obtain detailed data on the care given to a long-term mentally ill patient. The main data-collection instrument was an interview guide for the individual interviews. A questionnaire was used to collect demographical data.

3.4.4.1 Interviews

Data was collected through the interviews until data saturation was reached, when no new information, themes or categories emerged (Polit & Beck 2008:357).

An interview is a structured or unstructured oral communication between the researcher and the participant to obtain information for a study (Brink et al 2008:204; Burns & Grove 2009:705). Unstructured face-to-face interviews are also known as the in-depth interviews and were conducted to collect rich data from the participants. The interviews were conversational and interactive, and allowed the researcher to collect data specific to the phenomenon.

According to Greeff in De Vos et al (2005:287), researchers conduct face-to-face interviews because of an interest in other people's stories as a way of learning from different situations. By using an interview guide the researcher understood the world from the participants' point of view, known as the emic perspective and unfolded the meaning of the reality of their world. An interview guide was used to collect data using a "grand tour": Tell me about your experiences in caring for your mentally ill relative.

The researcher also asked probing questions during interviews as determined by the flow of conversation to encourage the participants to continue talking about their present and past experiences and situational factors relevant to the investigation. For example:

- What challenges do you experience in caring for your long-term mentally ill family member?
- How do you handle these challenges?

Family experiences in caring for a mentally challenged family member may be both positive and negative.

3.4.4.2 Direct observation

Observation is a technique for collecting descriptive data on behaviour, events and situations (Brink et al 2008:143). Observation may be structured or unstructured. In unstructured observation, the researcher describes events or behaviours as they occur (Brink et al 2008:205). Observation allows a researcher to gather a variety of information, including individuals' characteristics and conditions, verbal and non verbal communication, activities and behaviour and environmental conditions (Polit & Beck 2008:370).

The shortcomings of observation include ethical difficulties, distorted behaviour when participants are aware of being observed, and observer-bias. Observer-bias includes observers' emotions, prejudice, attitudes, personal interests and commitments. Anticipation of what is to be observed may affect what is observed, and hasty decisions before adequate information is collected may result in erroneous conclusions (Brink et al 2008:145-146; Polit & Beck 2008:370).

In this study, observation was used to note and record the participants' non-verbal expressions and cues during the individual interviews. Observation of the family's behaviour and the setting in which they lived was noted. Also verbal responses that correlated with occasional nodding, e.g. "mm-mm, yes, I see," were used to show the participants that the researcher was listening (Greeff in De Vos et al 2005:289).

3.4.4.3 Questionnaire and interview guide

A questionnaire was used to collect the participants' demographical data, including age and gender. The aim of the study was to determine the experiences of family members caring for a long-term mentally ill person and the meaning of the experiences attached to it. Therefore the researcher used an unstructured interview guide with one open-ended question: "What are your experiences in caring for a long-term mentally ill relative?" The researcher used probing questions until data saturation occurred and the participants' experiences were thoroughly described. The participants were encouraged

to talk about their experiences and feelings about caring for their mentally ill relative and the support offered. A moderator was also present during data collection.

3.4.4.4 Pilot study

A pilot study helps researchers to identify problems in the design of questions, sequencing of questions, or procedure for recording responses (Polit & Beck 2008:762). Pre-testing of the data-collection instrument was done on one family caring for a long-term mentally ill patient. The participants were identified through the hospital records and an appointment was made to visit and interview them. The family that participated in the pre-test was not included in the main study. The researcher also had an opportunity to practise interviewing skills and the use of the tape-recorder.

The pre-test enabled the researcher to identify problems in data collection. For example, the mentally ill patient initially disrupted the interview although she later cooperated. Some probing questions had to be reformulated and simplified for the participants to understand.

3.4.4.5 Bracketing

The researcher used bracketing to avoid misinterpreting the phenomenon. Bracketing is a way of suspending or laying aside what is known about the experiences of the family members caring for a long-term mentally ill patient (Brink et al 2008:113; Burns & Grove 2009:545). The researcher attempted to bracket out the world and any presuppositions in an effort to confront the data in a pure and objective form (Polit & Beck 2008:228).

The researcher kept a journal to record all thoughts, opinions and preconceived ideas about the phenomenon and experience as a nurse educator and clinical nurse practitioner. All the recorded information was put aside before conducting the study, and during data collection and analysis. These procedures were intended to facilitate openness and new insights.

3.4.5 Data-collection process

Before commencing, the researcher obtained permission and consent from the participants to use a tape recorder during the interviews. Data was properly labelled with dates, places and numbers, no personal information was written on the labels for confidentiality purposes.

The participants were Tsonga speaking, which is also the researcher's home language. The individual interviews were conducted in the participants' home setting. This also gave the researcher an opportunity to observe the participants' world and to take observational notes. A room away from other family members to avoid distractions was provided for the interviews, and there were no interruptions like telephone calls. Interviews were held with all the family members who fulfilled the criteria. A relaxed environment was created by making small talk with the participants to set them at ease and to establish rapport.

The participants were allowed to tell their stories with little or no interruptions. They freely expressed their lived experiences, feelings, fears, anxieties and beliefs and attached meanings to those experiences. The participants were also encouraged to elaborate on particular dimensions of the topic, such as dealing with violence as it was a category that frequently emerged during the interviews.

3.4.5.1 Communication strategies during interviews

The researcher used paraphrasing, clarification and reflection as communication strategies to facilitate data collection and analysis.

- Paraphrasing involved verbal responses in which the researcher enhanced meaning by stating the participant's words in another form with the same meaning (Greeff in De Vos et al 2005:289).
- Clarification was used to gain clarity on all unclear statements; for example, "Can you tell more about it?"
- Reflection was done on important issues that the participant had just said in order to get them to expand on the idea or point under discussion (Greeff in De Vos et al 2005:289).

3.4.5.2 Note-taking during the interview

Before the start of each interview session the researcher informed the participants that notes would be taken during the interview. However, most of the time note taking was done after the interviews to avoid distracting the participants. Although the interviews were audio-taped, a field diary was also used and field notes taken during the interview to document information and any non verbal cues evidenced by the participants as they answered questions.

A field diary was used during the data collection session to record events and conversation in the field. This was useful for the researcher's insights to be recorded as they occurred as well as for personal responses to events encountered (Burns & Grove 2009:519).

3.4.5.3 Field notes

Field notes are notes taken by researchers to record the unstructured observations made in the field, and the interpretation of those observations (Polit & Beck 2008:754). Greeff in De Vos et al (2005:311) describes field notes as "a written account of the things the researcher hears, sees, experiences and thinks in the course of data collection". Field notes are both *descriptive* and *reflective*. According to Polit and Beck (2008:406), descriptive or observational notes are objective descriptions of observed events and conversations whereas *reflective* notes document the researcher's personal experiences, reflections and progress while in the field. Reflective notes were kept separately and used for the purposes of bracketing. The researcher kept methodological, theoretical or analytical, and personal field notes.

- **Methodological notes** are reflections about strategies and methods used in observation. They provide instructions or reminders about how subsequent observations will be made (Polit & Beck 2008:406). In this study, the researcher used unstructured observation to describe events or behaviours as they had occurred.
- **Theoretical or analytical notes** document the researcher's thoughts about how to make sense of what is going on and attach meaning to observations while in

the field as it serve as a starting point for subsequent analysis (Polit & Beck 2008:406). The researcher kept notes detailing the interpretations of the behaviours that were observed.

- **Personal notes** are comments about the researcher's own feelings while in the field. Personal emotions can challenge the researcher's assumptions, and must be reflected in order to determine whether the feelings influence what is observed or what is done (Polit & Beck 2008:407). In this study, field notes were written as soon as possible after the observation to avoid forgetting important information. The participants lastly asked for a follow-up session, and were referred to the hospital to be seen by the multidisciplinary team.

3.5 DATA ANALYSIS

Data analysis is a process of bringing order, structure and meaning to the mass of the qualitative data that was collected (De Vos in De Vos et al 2005:333). In qualitative research data analysis begins during data collection, and continues until the end of the study. The data collected in this study was non-numerical, in the form of written and tape-recorded transcripts. The audio-taped information was transcribed verbatim. By transcribing the interviews and observational notes, the researcher had an opportunity to become immersed in the data and generated deeper insight into the phenomenon.

Tesch's (1990) eight-step method (Creswell 1994:155) was used to analyse the data as indicated below:

- All the typed transcripts which were transcribed verbatim from the audiotape were read through in order to get a sense of the whole and the ideas were written down in the margin.
- The underlying meaning was identified in the individual interviews. Themes, categories and sub categories that emerged were written down.
- A list of all categories that were identified from the data was clustered to make sense.
- These categories were utilised as codes. A code is a symbol or abbreviation used to classify words or phrases in the data (Burns & Grove 2009:522).
- Descriptive wording for the topics was found and arranged into categories.
- The codes were arranged in alphabetical order.

- Data was grouped under different categories as codes to enhance analysis. The participants' direct quotes were used as units of analysis.

Themes, categories and sub categories were identified and a final analysis report was written. A conceptual map emerged from the identified patterns of the recorded experiences

3.6 ETHICAL CONSIDERATIONS

Ethics deals with matters of right and wrong. *Collins English Dictionary and Thesaurus* (1995:533) defines ethics as "a social, religious, or civil code of behaviour considered correct, especially that of a particular group, profession, or individual". Research that involves human beings as participants should be conducted in an ethical manner to protect their rights. Polit and Beck (2008:167) emphasise that when individuals are used as study participants, "care must be exercised in ensuring that the rights of the participants are protected". Accordingly, the researcher obtained permission to conduct the study, obtained informed consent from the participants and respected their right to self-determination, privacy, anonymity and confidentiality, and to fair treatment (Burns & Grove 2009:196).

3.6.1 Permission

The researcher obtained permission from the Research Ethics Committee of the Department of Health Studies of the University of South Africa (see annexure A) and from the Department of Health and Social Development, Limpopo Province, South Africa (see annexure D). The rights of the research institution where the sample was drawn from were protected by requesting permission to conduct the study (see annexure C).

3.6.2 Informed consent

Informed consent means that the participants have adequate information regarding the research, are capable of comprehending the information, and have the power of free choice, enabling them to consent or to decline participation voluntarily (Polit & Beck 2008:176). The researcher informed the participants of the nature and purpose of the

study; that participation was voluntary, and that they were free to withdraw from the study at any time if they so wished (Burns & Grove 2009:201). The researcher also assured the participants of their right to privacy, anonymity and confidentiality, self-determination, and fair treatment. The participants then signed informed consent forms (see Annexure F[i] and F[ii]).

3.6.3 Privacy, anonymity and confidentiality

Privacy is the freedom from intrusion by the public (*Chambers English Dictionary* 2006:1211). It is an individual's right to determine the time, extent and general circumstances under which personal information will be shared with or withheld from others (Burns & Grove 2009:194; Stuart 2009:129). Based on the right to privacy, participants have the right to anonymity and the right to assume that the data collected is kept confidential (Burns & Grove 2009:196). To protect the participants' privacy, anonymity and confidentiality, the researcher used numbers instead of names. Confidentiality was assured because the researcher informed the participants that the information would not be shared with anyone other than the researcher's supervisor and the institutions connected with the study. Each tape was marked with the date, location and number of the interview, the number referred to the patient. In addition, the audio-tapes and transcripts and demographical forms were stored in a safe place only accessible to the researcher. The audio-tapes will be destroyed two years after publication of the research.

3.6.4 Self-determination

The right to self-determination is based on the ethical principle of respect for persons, which indicates that because individuals are capable of self-determination, or controlling their own destiny, they should be treated as autonomous agents who have the freedom to conduct their lives as they choose without external controls (Burns & Grove 2009:189).

In this study the participants were treated as autonomous agents and were allowed to voluntarily choose to participate or not. The participants were free to ask questions, to refuse to give information or to withdraw from the study at any time without penalty. The

participants were not offered incentives to encourage them to participate in the study and no penalty or threat was held for those who chose not to participate.

Since the participants were between the ages of 10–60 years old, the children's right to self-determination was also protected during the study process by giving appropriate information on the study purpose and expectations. Parents gave consent for children who were minors to participate in the study (see annexure F [ii]).

3.6.5 Fair treatment

The right to fair treatment is based on the ethical principle of justice, which holds that each person should be treated fairly and should receive what is due or owed (Burns & Grove 2009:198). Polit and Beck (2008:173) add that the selection of participants should be based on research requirements and not on their vulnerability.

The participants were selected fairly, as they were selected for reasons directly related to the problem being studied and not for their easy availability. Fair treatment of the participants was also ensured by being punctual for the appointments. The privacy, anonymity and confidentiality of the children who participated were also ensured.

3.6.6 Scientific integrity of the study

Scientific integrity refers to honest practices commonly accepted within the scientific community for proposing, conducting or reporting research (Brink et al 2008:40). The researcher acknowledged all sources and references used in the study as well as all the individuals and institutions who contributed to the study, presented the findings without falsification and/or fabrication of information, and personally prepared the dissertation herself. The measures which the researcher applied to enhance the trustworthiness of the study also served to ensure its scientific integrity.

3.7 MEASURES TO ENSURE TRUSTWORTHINESS

Scientific rigor in qualitative studies is measured by its trustworthiness or the extent to which the findings are true to the data and the research context. The aim of scientific research is to minimise contamination of the results by external factors (Bowling

2002:118). Trustworthiness is ensured by credibility, dependability, confirmability and transferability (De Vos in De Vos et al 2005:346).

3.7.1 Credibility

Credibility refers to maintaining confidence in the truth and interpretation of the data. The truth of the findings was established as the participants were accurately identified and described and the data was obtained from participants who had personal experience (Polit & Beck 2008:539). The researcher's credibility has to do with the faith and trust that can be put in the researcher (Polit & Beck 2008:538). The researcher has several years' experience as a qualified mental health nurse and a lecturer at a nursing college teaching psychiatric nursing. The researcher ensured the credibility of the study through prolonged engagement, persistent observation, reflexive analysis, peer debriefing, and triangulation. In this study, however, the researcher did not do member checking because the participants feared that a second visit to the family might arouse suspicion among neighbours. In a member check, researchers provide feedback to study participants about the emerging interpretations and to assess the participants' reactions (Polit & Beck 2008:545).

- *Prolonged engagement.* Prolonged engagement refers to the investment of sufficient time in data collection and analysis activities to obtain an in-depth understanding of the culture, language, views or opinions of participants (Polit & Beck 2008:542). The participants were allowed to verbalise their feelings without being hurried or interrupted. The interviews were conducted until data saturation was reached. During data analysis, the researcher listened to the tape recordings over and over again, wrote and re-wrote the transcripts, then read and re-read them to comprehend the data.
- *Persistent observation.* Persistent observation refers to the researcher's focus on the aspects of the situation that are relevant to the phenomenon being studied (Polit & Beck 2008:542). During and after the interviews, the researcher was able to observe the environment and how the family members interacted with each other, and noted details of what and how they communicated to each other.
- *Reflexive analysis.* Reflexive analysis refers to the need to critically think through the dynamic interaction between the self and the data occurring during analysis (Burns & Grove 2009:545). The researcher put aside personal feelings and

experiences that might have influenced the study and used bracketing to avoid misinterpreting the phenomenon of the participants' experiences.

- *Peer debriefing.* Peer debriefing entails holding sessions with peers to objectively review and explore various aspects of the inquiry (Polit & Beck 2008:548-549). In this study, the researcher presented the tape-recorded interviews with written summaries of the data collected, categories and themes that emerged from the data to the research supervisor.
- *Triangulation.* Triangulation was ensured by the use of multiple data-collection methods and references to draw conclusions on what constituted the truth and reality (Polit & Beck 2008:543). Bias was overcome by applying the use of a biographical questionnaire, unstructured interviews, field notes and direct observation during data collection.

3.7.2 Dependability

Dependability refers to the stability of collected and analysed data over time and specific conditions (Polit & Beck 2008:539). In this study, the audio-taped information and field notes served as evidence that it remained consistent and stable. A dense description of the research method was provided. In each interview the same question was posed to the participants to ensure step-wise replication of the research method. In data analysis code-recode of the data took place.

3.7.3 Confirmability

Confirmability refers to objectivity that is the potential congruence between two or more independent people about the accuracy, relevance and meaning of the data. In this study data collection and analysis represents the information provided by participants and not manipulated data by the researcher. The audio-taped information and field notes serve as evidence to reflect the participants' responses (Polit & Beck 2008:539).

3.7.4 Transferability

Transferability refers to the extent to which findings can be transferred or applied to other similar settings or groups. The findings of this study cannot be generalised as it was conducted with one family identified from one hospital, although the descriptions

and results could assist researchers to consider transfer as a possibility (Polit & Beck 2008:539). A dense description of the demographic information of the participants was provided. A rich description of results with supporting quotations from the participants was given.

3.8 CONCLUSION

This chapter discussed the research design and methodology, including the setting, population, sampling, sample, data collection and analysis, measures to ensure trustworthiness and the ethical considerations.

Chapter 4 describes the data analysis and interpretation.

CHAPTER 4

Data analysis and interpretation

4.1 INTRODUCTION

After describing the research design and methodology in chapter 3, this chapter discusses the data analysis and interpretation of the findings.

4.2 DATA MANAGEMENT AND ANALYSIS

Qualitative data analysis occurs concurrently with data collection by gathering, managing and interpreting data (Burns & Grove 2007:79).

4.2.1 Data management

In qualitative research data management is reductionistic as it involves converting large masses of data into smaller, more manageable segments (Polit & Beck 2008:515). The data was collected by in-depth individual interviews which were tape-recorded and transcribed verbatim. To protect the participants' privacy, anonymity and confidentiality, the researcher used numbers and not the participants' names. Each audio tape was marked with the date, location and number; for example, 15/08/2011, Limpopo/3. This represented the date of the interview, the name of the setting and the number of the participant taking part in the interview. The audio-tapes, transcripts and demographical forms were stored in a safe place only accessible to the researcher. The tape-recorded interviews were transcribed word for word and translated into English because the participants were Tsonga speaking. The researcher typed, carefully coded and filed the data. The transcripts indicated who was speaking, namely the interviewer and the participant. Transcribing the interviews and observational notes gave the researcher an opportunity to become immersed in the data and gain a deeper insight into the phenomenon.

4.2.2 Data analysis

Data analysis refers to a search for patterns in data, recurrent behaviours, phrases or ideas (Neuman 2006:467). Tesch's (1990) eight-step method (Creswell 1994:155) was used to analyse the data. Two themes, four categories and eight subcategories were finally identified (see table 4.2). A conceptual map emerged from the identified patterns of the recorded experiences.

4.3 PARTICIPANTS' PROFILE

The researcher used a genogram and the biographical data to gain a full picture of the participants.

4.3.1 Genogram for family assessment

A genogram is a diagrammatic, historical map of a family (Kneisl & Trigoboff 2009:821). The diagram assisted the researcher to understand the family under study and the patient's development, genealogical relationships and their current social interaction patterns. Figure 4.1 depicts the genogram of the participants.

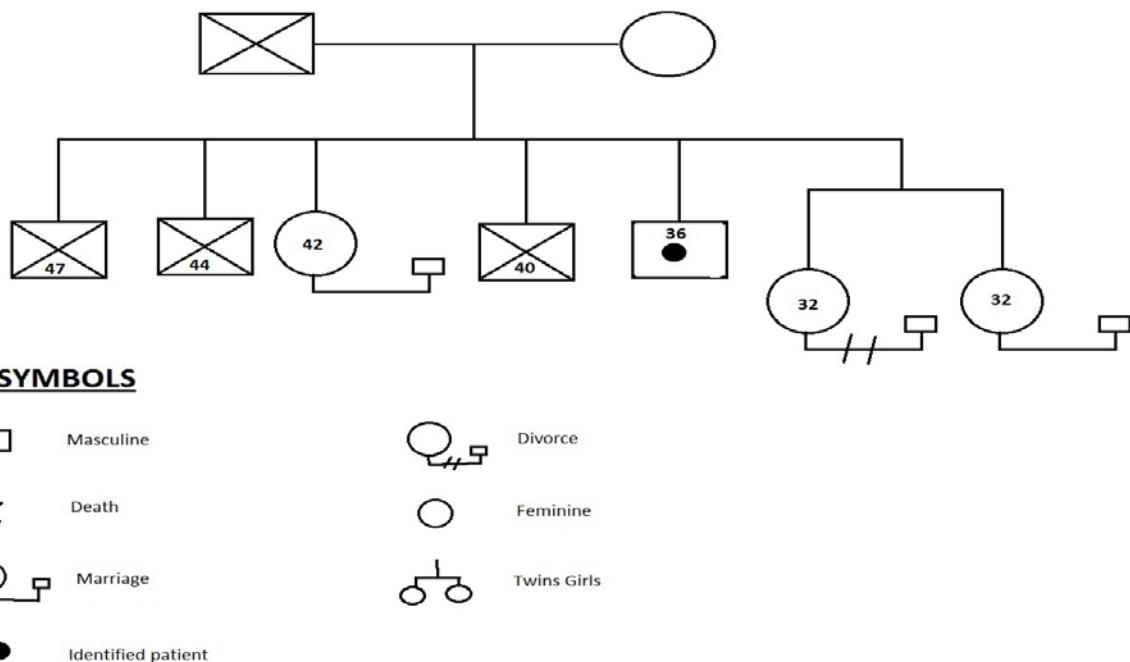


Figure 4.1 Genogram for family assessment

(Adapted from Kneisl & Trigoboff 2009:821)

The family comprised of a mother, a mentally ill patient, a daughter and a grandson. The 60 year-old mother had seven children: four sons and three daughters. The father died eleven years ago from natural causes. Three of the sons were also deceased: one had died fourteen years ago at 47 years of age; the second one had died six years ago at 40 years of age, and the third one had died four years ago at 44 years of age. The 40 year-old son who died six years ago had been diagnosed with mental illness. The remaining son who is alive is 36 years old and is a patient diagnosed with schizophrenia. Of the three daughters who are alive, two are married and one is divorced. The mother, the mentally ill patient, the 32 year-old divorced daughter, and a grandson all lived together in the family home.

4.3.2 Participants' biographical information

The biographical information consisted of the participants' age, gender, qualifications (educational level), employment and marital status. The data was analysed quantitatively and described in frequencies and percentages. Table 4.1 lists the participants' biographical data.

Table 4.1 Participants' biographical details

Parameter	Value	Frequency	Percentage
Gender n=4	Female	3	75%
	Male	1	25%
Age n=4	0-10	0	0
	11-20	1	25%
	21-30	0	0
	31-40	2	50%
	41-50	0	0
	51-60	1	25%
Marital status n=4	Married	1	25%
	Single	1	25%
	Divorced	1	25%
	Widow	0	25%
	Widower	1	0
Qualifications n=4	Primary level	2	50%
	Secondary level	2	50%
	Tertiary level	0	0
Employment status n=4	Unemployed	1	25%
	Employed	2	50%
	Self-employed	0	0
	Retired	1	25%
Relationship to the mentally ill patient n=4	Father	0	0
	Mother	1	25%
	Brother	0	0
	Sister	2	50%
	Son	0	0
	Daughter	0	0
	Nephew	1	25%
Duration of care n=4	0-2 years	0	0
	3-4 years	0	0
	5-6 years	0	0
	>7 years	4	100%

The participants, three were females and one was male. The nephew, two sisters and the mother, who cared for the mentally ill patient for more than seven years, participated in the study.

The participants' ages were, one was aged between 11 and 20, the other two were between 31 and 40, and the last one was 60 years old. One participant was single, one was married, one was divorced, and one was widowed. Regarding educational level, two of the participants had attended school up to secondary level; one had attended up to primary level, and one was in Grade 7 at present. Two of the participants worked in a local factory, one had retired, and one attended school. This family size was small but their income status predisposed them to be financially marginalised contributing to their financial struggles and constraints at home.

4.3.3 Themes, categories and subcategories

The data analysis began with a search for broad categories or themes. Polit and Beck (2008:515) define a theme as an abstract concept that brings meaning and identity to a current experience and its variant manifestations. A theme captures and unifies the nature or the basis of the experience into a meaningful whole. Themes emerge from the data and develop within the categories of the data. The researcher identified two themes, four categories and eight subcategories from the data collected (see table 4.2).

Table 4.2 Summary of the themes, categories and subcategories

Theme	Category	Subcategory
Theme 1: Family involvement in caring for the long-term mentally ill patient	1.1 Provision of basic care 1.2 Involvement of the family in caring for advanced needs 1.3 Challenges related to social factors	1.1.1 Provision of basic needs 1.3.1 Financial support 1.3.2 Psychosocial support 1.3.3 Cultural factors
Theme 2: Relating with the mentally ill patient	2.1 Relationships with different groups	2.1.1 Relationship with the family 2.1.2 Relationship with health professionals 2.1.3 Relationship with members of SAPS 2.1.4 Relationship with the friends and neighbours

Table 4.2 indicates the themes, categories and subcategories generated from the data that directed the analysis and interpretation of data. The themes are discussed with reference to the literature reviewed. The data was collected from each individual participant.

The participants' responses to the question of what their experiences were of caring for a long-term mentally ill patient and probing questions enabled the researcher to relate to what constitutes caring for a mentally ill patient and the challenges experienced as the care was provided.

4.4 THEME 1: FAMILY INVOLVEMENT IN CARING FOR THE LONG-TERM MENTALLY ILL PATIENT

Caring is a process of providing a substantial amount of care or support on a regular basis to another person, because of age, disability or illness, when managed in an institution or at home (*Blackwell's Nursing Dictionary* 2005:109).

In this study, caring referred to the participants' care and support for their long-term mentally ill patient at home. In the context of mental illness, care denotes providing person-centred care in which individuals are enabled to make the best use of their personal and financial resources in facing and coping with needs, fears and questions which arise in a home situation when caring for a schizophrenic patient. Family members caring for a long-term mentally ill patient are thus required to be directly involved in caring for their basic needs, and deal with the challenges encountered when providing such care (Uys & Middleton 2010:84). Table 4.3 indicates the themes, categories and meaning units of family involvement in caring for a long-term mentally ill patient.

When mental illness develops in a family, the physical, emotional and financial strain of the illness disrupts their quality of life. Patients with schizophrenia present a challenge to general care. Caring by family members is different from the care provided by others because caring in this sense goes beyond helping and looking after someone in need. The family of the patient with mental illness shoulders the greatest part of the burden of caring, and are the patients' main resource.

Table 4.3 Family involvement in caring for the long-term mentally ill patient

Category	Subcategory	Meaning unit
1.1 Provision of basic care	<ul style="list-style-type: none"> 1.1.1 Provision of basic needs <ul style="list-style-type: none"> • Need for food • Need for shelter • Need for basic hygiene • Need for safety • Coping strategies 	<p><i>"When he is well, he eats too much, but when he has relapsed, when he is given food, he just throws it away."</i></p> <p><i>"It is his room, and he broke the window pane."</i></p> <p><i>"Ever since he came back from hospital he does not bath."</i></p> <p><i>"He does not even bath or cut his hair and his hair grows long and matted because he does not comb it."</i></p> <p><i>"He destroys household utensils and furniture and throws them to the neighbours' houses. He also throws stones which can hurt. When he is like that no one approaches him, we leave him and he remains alone."</i></p> <p><i>"If I was responding to his accusations, he would have injured me long ago. We just run away. My grandmother would go to the police station."</i></p>
1.2 Involvement of the family in caring for advanced needs	<ul style="list-style-type: none"> • Involvement with regard to treatment 	<p><i>"Now because his condition is stable he does take his tablets."</i></p> <p><i>"He sometimes refuses to take his prescribed tablets but, if he is taken to the hospital and he is given 'that' injection he suddenly becomes fine."</i></p>

Category	Subcategory	Meaning unit
	<ul style="list-style-type: none"> • Involvement with regard to relapse 	<p><i>“Another man gave him a cigarette mixed with nail polish. After smoking, he became worse again, also when he smokes the ‘green cigarette’. When he relapses, he takes off his clothes and remains stark naked. When he is given food, he just throws it away. He would throw stones at us or anything he finds.”</i></p>
1.3 Challenges related to socio-cultural factors	1.3.1 Financial support	<p><i>“Oh! The situation is difficult here, because we all depend on mother’s social grant.”</i></p>
	1.3.2 Psychosocial support	<p><i>“He is no longer receiving his grant money. His identity document (ID) is with the one who is abusing his money. When I tell him to go and collect his ID, he refuses. Those people opened a bank account for him in town where the money was then deposited and they had access to the money without informing us. So we informed the social worker. In the hospital they also said he relapses because of money. The social worker recommended that his disability grant be stopped because it was no longer assisting.”</i></p>
	1.3.3 Cultural factors	<p><i>“I found that he had dug in front of the door and put some herbs so that I die. I found these herbs while I was sweeping the yard hidden under some stones.”</i></p>
	<ul style="list-style-type: none"> • Heredity 	<p><i>“It was not only him, but also our elder brother had the same condition of mental illness.”</i></p> <p><i>“From my maternal family there is no one who has this condition. Even from within my husband’s family I do not remember of anyone who is</i></p>

Category	Subcategory	Meaning unit
	<ul style="list-style-type: none"> • Culture 	<p><i>suffering from mental illness. This illness only came to him and his brother who passed away a few years ago."</i></p> <p><i>"When he came back from one of the meetings he informed our father that in those African National Congress (ANC) meetings his name was mentioned as among those who were suspected of practising witchcraft. It started then, so we believed this has not been caused by outsiders; it is from within our family."</i></p> <p><i>"He extended his hand to greet him. Once he was touched by his father he just started taking off his clothes and when the traditional healer came home in the evening he found him just like that, and heard him saying, "father ... father ... father ..."</i></p>

Uys and Middleton (2010:88) identify different stages of care giving, some of which were revealed in the study.

- *Perceiving a problem:* The patient in this study had already been ill for seven years. However, the family members could identify this stage when they realised that something was wrong with the person. The problem became serious and was still present. The patient started showing signs of mental illness, talking alone and laughing inappropriately:

"It is when he does not come out of his room and will not speak to anyone; he would sleep for abnormally long hours, and refuses to eat. When it is like this we can easily see that the condition is changing from stable to bad."

- *Searching for solutions:* During this stage the participants searched for information and assistance as revealed by one participant when the mentally ill

patient was taken to different witch doctors and lastly to the hospital (Uys & Middleton (2010:88).

"There is no place they do not know [him]. This one [the patient] can even tell that he knows the house of Thomas Hasani Chauke (Xinyori); we passed there when we went to Mhinga. He was taken to a traditional doctor who had just started the trade, but later we decided to rely on the hospital."

- *Enduring the situation:* The participants seemed to endure the situation as they were focused at that stage and got information from personal experience (Uys & Middleton 2010:88):

"No, but I observe that with the care of the hospital he is now fine. The hospital is always doing its best because when he is here at home, he does not even bath or cut his hair and his hair grows long and matted because he does not comb it. When he is at the hospital, he cuts his hair, washes himself and he is clean. There he eats and takes his tablets. At the hospital he is controllable because when one speaks to him he is willing to listen."

- *Surviving the experience:* Acceptance of the condition decreased guilt and led to increased support and understanding by health professionals, police, friends and neighbours. The study revealed that all the participants were supportive of the mentally ill patient as best as they could with the use of available resources or help (Uys & Middleton 2010:88).

"We buy him clothes and food. My grandmother and I are the ones who normally give him tablets."

The participants showed an understanding of the mentally ill patient's situation by continuing to provide care despite the unacceptable behaviour.

According to Uys and Middleton (2010:431), the family as a group plays an important role in the functioning of a patient and every member should be encouraged to take responsibility for the patient's rehabilitation and be fully involved. In this study, although the family tried to intervene with care and concern, the frequency of relapse and

hospitalisation did not decrease. The provision of care was mainly focused on providing the basic needs.

Category 1.1: Provision of basic needs

The mentally ill patient's main basic needs were for food, shelter, basic hygiene and safety. One unmet basic need adversely affects all the other needs. Maslow's theory of human needs is also used in psychiatric mental health nursing (Boyd 2008:60) (see figure 4.2). Maslow advocated viewing human behaviour from a perspective of needs and the hierarchy of needs range from basic food, shelter and warmth, safety, belonging and self-esteem needs to a higher level requirement for self-actualisation. The participants indicated that their basic needs were food and clothes, shelter, basic hygiene, safety and how to avoid being injured by the patient when he became violent. The participants also understood the need to transcend the problem by seeking help outside or beyond themselves from witchdoctors and health care providers (Boyd 2008:60).



Figure 4.2 Maslow's hierarchy of needs

(Adapted from Boyd 2008:61)

- **Need for food and clothes**

Perese (2010:43-56) found that among patients with mental illnesses such as schizophrenia, the need for food was not often reported as unmet. In this study, the participants indicated that they provided the mentally ill patient with food, although at times he refused the food or threw it away:

"When he is well, he eats too much, but other times when he is given food, he just throws it away."

The participants indicated that one of the married daughters lived close to the family home and checked regularly on whether the mentally ill patient was eating, bathing and taking the prescribed medication. One participant indicated that good family involvement was exemplified by:

"We buy clothes and food for him."

It was noted that although the mentally ill patient did not need total care from the participants, one family member always had to be at home to ensure that food was prepared and that the patient took the medication at the correct time. Although caring for the patient was challenging, all the participants in this study were involved in the care in some way.

- **Need for shelter**

Recovery begins with appropriate housing, although the need for appropriate housing is mostly unmet (Perese 2010:43-56). One participant indicated that the mentally ill patient had broken the window of the room that they were building for him. A bed and chair were also broken. The researcher observed the broken window although the room was not complete due to financial constraints:

"You can see that window, it is his room, and he broke the window pane."

Consequently, the mentally ill patient was using a room in his mother's house, however at times he relapsed and chased the mother out of her own house.

Schizophrenia is a risk factor for homelessness and living on the streets for many reasons such as additional stressors. Shelter is an essential factor in promoting recovery as it ensures privacy and safety. Boyd (2008:742) emphasises that without a dwelling place, meeting basic needs is difficult.

- **Need for basic hygiene**

The participants reported that the mentally ill patient did not bathe even if they prepared water for him, did not change his clothes, and left his hair long, matted and untidy. It was only when the patient was admitted to hospital that he bathed, changed clothes and shaved. Sometimes the patient also wet the bed at night:

"Ever since he came back from hospital he does not bath, he also wets his bed."

Kneisl and Trigoboff (2009:386) indicate that persons with schizophrenia may neglect to bathe, change their clothes and attend to minor grooming tasks such as combing their hair. Although Kneisl and Trigoboff (2009:386) state further that disregard for appearance and hygiene may extend to the client's environment, the researcher observed that the participants' home surroundings were clean.

- **Need for safety**

Keltner et al (2003:279) state that safety is freedom from danger or harm and encompasses freedom from both psychological and physical harm. The participants indicated that the patient sometimes became very violent, throwing stones and breaking furniture. They reported that the patient became a danger to himself, others and property. The participants reported the patient's aggressive behaviour as follows:

"He destroys household utensils and furniture and throws them to the neighbours' houses. He also throws stones which can hurt. When he is like that no one approaches him, we leave him and he remains alone."

At times the patient's mother was also not safe:

"He would chase me away, then take off his clothes and remain naked. He would even forbid me from entering his room."

Stuart (2009:355) indicates that patients can harm themselves because of impaired judgment or as a response to hallucinations and delusions.

All the participants indicated that the use of dagga precipitated mental illness. However, family members gave the mentally ill patient tobacco to beg him to take medication and friends gave him dagga. Following the use of dagga, the patient became physically and verbally aggressive; broke furniture; roamed around naked at night, and refused to bath and take his medication. According to Kneisl and Trigoboff (2009:348), the use of substances may further result in increased psychiatric symptoms, poor treatment adherence, and chronic threats to health, behavioural problems and violence. Fortinash and Worret (2008:322) found that after smoking cannabis, the psychoactive effects were followed by other signs such as increased appetite.

- **Coping strategies for safety**

Coping is a process by which an individual attempts to alleviate, relieve or remove stress or threat and may consist of a large array of covert and overt behaviours (Uys & Middleton 2010:28). Kneisl and Trigoboff (2009:146) define coping strategies as a set of behaviours persons under stress use in struggling to improve their situations. Coping is a conscious process of what people do when they have a problem. The coping strategy chosen depends on the person's assessment of the threat and external resources available, such as money. The participants shared the following coping strategies:

- Keeping silent when the mentally ill patient was insulting.
- Buying "BB" tobacco when he refused medication to encourage him to take it.
- Running away from home.
- Calling the police for assistance.

According to the participants:

"If I responded to his accusations, he would have injured me long ago."

"We just run away; my grandmother would go to the police station."

The study revealed that through experience, people develop strategies to cope in a situation. Most often individuals use behaviours that have worked for them in the past or they behave in a certain way because it is the only method they have of coping or because other coping strategies failed to work (Kneisl & Trigoboff 2009:146).

Category 1.2: Involvement of the family in caring for advanced needs

Poor adherence to treatment may be due to patient-related factors such as substance abuse, forgetfulness, anxiety about the side effects of drugs, inadequate knowledge, and the lack of insight and motivation (Kazadi , Moosa & Jeena 2008:52-62). However, the family is challenged to seek information on how to be effectively involved in order to ensure that treatment is adhered to prevent relapse.

- **Involvement in treatment**

Patients who do not take their medication as prescribed are at risk for unsuccessful results and poor quality of life (Stuart 2009:532). Stuart (2009:532) found that threats to treatment adherence arose from mental health teams, patients, and their families. Furthermore, Stuart (2009:532) states that clinicians blame the patient's family for non-adherence without completing the following:

- Evaluating the treatment plan from the patient and family perspective.
- Aligning the treatment plan with the patient's family goals.
- Understanding the patient and family's reason for non-compliance.

The participants reported refusal of treatment by the mentally ill relative. When dagga was abused, compliance to treatment was poor. The mother bought "BB" tobacco for the patient to encourage him to take the medication in the belief that tobacco is not as strong as dagga. Due to poor compliance, one participant suggested the use of injectables:

"If he is taken to the hospital and he is given 'that' injection he suddenly becomes fine."

Sadock and Sadock (2007:489) point out that compliance increases when long-acting medication is used instead of oral medication. Boyd (2008:299) emphasises that adherence to a prescribed medication regimen is the best approach to preventing relapse and the use of long-acting injectables is expected to improve compliance outcomes since many patients stop taking medication on their own.

- **Involvement in relapse**

Relapse in schizophrenia is recognised as the re-emergence or the worsening of psychotic symptoms. However, Kneisl and Trigoboff (2009:377) state that a patient with schizophrenia is vulnerable to a return of symptoms after a period of stability, and the disease itself has a pattern of relapse and recovery. Kazadi et al (2008:52-62) identified two criteria for relapse:

- Aggravation of positive or negative symptoms.
- Admission to hospital in the past 6 months.

One participant reported that the mentally ill patient had frequent relapses within a period of less than two months with hospital re-admissions:

"From the time of his release from hospital, he would be fine for less than two (2) months."

Recurrent relapse leading to long-term psychological and social disabilities means that patients may require intensive community support. Boyd (2008:757) states that relapse leads to repeated hospitalisation, and when symptoms of the mental disorder are stabilised, the hospitalised patient is discharged. Once in the community, if the patient fails to follow the prescribed medication and resumes the use of alcohol and drugs, the reappearance of symptoms leads to another episode of hospitalisation.

Kazadi et al (2008:52-62) confirm that the factors associated with relapse include poor adherence to treatment, substance abuse and stressful life events. Stressful life events are often associated with the onset of a psychotic relapse. Life stressors may be both internal and external. Patients with schizophrenia are more sensitive and susceptible to the negative effects of minor stressors (Kazadi et al 2008:52-62).

- **Substance abuse**

Substance abuse is common among patients with schizophrenia and refers to continued use despite related problems, and can lead to relapse (Stuart 2009:415). Commonly abused substances include nicotine, alcohol, cannabis and cocaine. Cannabis is a significant factor that contributes to relapse in all mental illnesses (Kazadi et al 2008:52-62). According to Jonsson (2008:97), substance abuse is often one of the reasons for relapse and readmission.

The participants observed signs of relapse as follows:

“Another man gave him a cigarette mixed with nail polish. After smoking, he became worse again, also when he smokes the ‘green cigarette’. When he relapses, he takes off his clothes and remains stark naked. When he is given food, he just throws it away. He would throw stones at us or anything he finds, we just run away.”

A wide variety of substances are available legally and illegally. The substances can be administered by any means or by any route into the body, bringing about impairment of mood, altered levels of perception and impairment of brain function. Substances are taken to escape from personal and psychological problems and confrontation with certain values and norms and may result in recurrent social or interpersonal problems like arguments, fights and relapse (Uys & Middleton 2010:445). Substance abuse may further result in failure to fulfil major role obligations, using substances in physically hazardous situations, and recurrent social and relationship problems (Kneisl & Trigoboff 2009:325).

Concerning substance abuse, a participant stated:

"I learnt that when he smokes, especially with dagga, his condition becomes worse and as such he would even leave home, no one would touch or control him. This is the dagga that they smoke when he is outside. Sometimes when he comes home his eyes are blood red. He would throw furniture around. These illnesses are dangerous if mixed with dagga."

Fortinash and Worret (2008:322) state that individuals usually smoke cannabis in cigarettes or pipes although some ingest it in food and psychoactive effects are followed by other signs within two hours of use such as conjunctival infection which is a blood shot appearance.

The participants in this study understood the effects of substance abuse on the patient's mental illness. Nevertheless, circumstances forced them to give the patient tobacco as replacement because he would not eat or take his medication unless he smoked.

Substance abuse is a co-occurring condition in persons with schizophrenia. Persons with schizophrenia often indulge in substances such as nicotine, caffeine and cocaine to self-medicate and to improve their attention span to deal with competing stimuli that are a constant disruption in their lives (Fortinash & Worret 2008:255). Nicotine relieves problems with sensory processing caused by schizophrenia and counteracts side effects of psychotropic medication which explains the high frequency of smoking (Kneisl & Trigoboff 2009:349).

Category 1.3: Challenges related to social factors that impact on support

Psychosocial support is the process of meeting a person's emotional, social, mental and spiritual needs in the context of the community. Appropriate psychosocial support helps the patient to overcome challenges and builds coping mechanisms, trust and hope in the future. Stanley and Shwetha (2006:113-128) indicate that the most common worries of relatives are about the patient's health, their own future, safety and financial position.

Subcategory 1.3.1: Financial support

People with schizophrenia have trouble handling money. In this study the mentally ill patient had received a disability grant until it was terminated. During the time that the grant was received, the patient was in charge of the money. However, the participants indicated that there was a person who had opened a bank account for the patient, and even the patient's ID was still with the particular person.

"He is no longer receiving his grant money. His ID is with the one who is abusing his money. When I tell him to go and collect his ID, he refuses. Those people opened a bank account for him in town where the money was then deposited and they had access to the money without informing us. So we informed the social worker. In the hospital they also said he relapses because of money. The social worker recommended that his disability grant be stopped because it was no longer assisting."

Boyd (2008:281) found that employment among people with schizophrenia is one of the lowest and the symptoms of the disease are so pervasive that it is difficult for these patients to maintain any type of gainful employment.

- **Financial constraints**

The participants indicated financial constraints in the family since the patient's disability grant was terminated although the money did not assist the whole family; the patient was able to take care of himself. The room that was being built for the patient was incomplete. The clothes that the patient wore were old and torn. The whole family depends and relies on the mother's pension grant because the two sisters are seasonal workers.

One participant indicated the need for assistance as follows:

"The only thing that we want is help so that he can get his disability grant again. He is giving us trouble here at home, there is no peace. He becomes so angry that he causes us a lot of pain. During those days that he used to get his grant money, he was able to afford the things he wanted. We do not have the money to buy him All Star takkies. With his grant money he used to buy for himself."

Gee, Pearce and Jackson (2003:1-11) found that the financial elements of schizophrenia fall into partial limitations which involve not being able to travel or go on holiday and failure to plan ahead. Experiential aspects such as being careful with money, a feeling of reduced choices and a sense of financial uncertainty also add to the financial elements of having schizophrenia (Gee et al 2003:1-11). Kotze (2007:28) emphasises the need for adequate resources to lessen the burden of caring for a mentally ill relative.

Subcategory 1.3.2: Psychosocial support

The challenges in this sub-category were about social stigma, safety, disruption in family life, and worry.

Although the participants did not indicate any label that was given to the family, it was sad to note that the mentally ill patient undressed in public because internal stigma starts within oneself. As soon as a family member presents with mental health symptoms and mental illness is diagnosed, stigma, social isolation and low self-esteem follow with resultant mental health challenges (see figure 4.3).

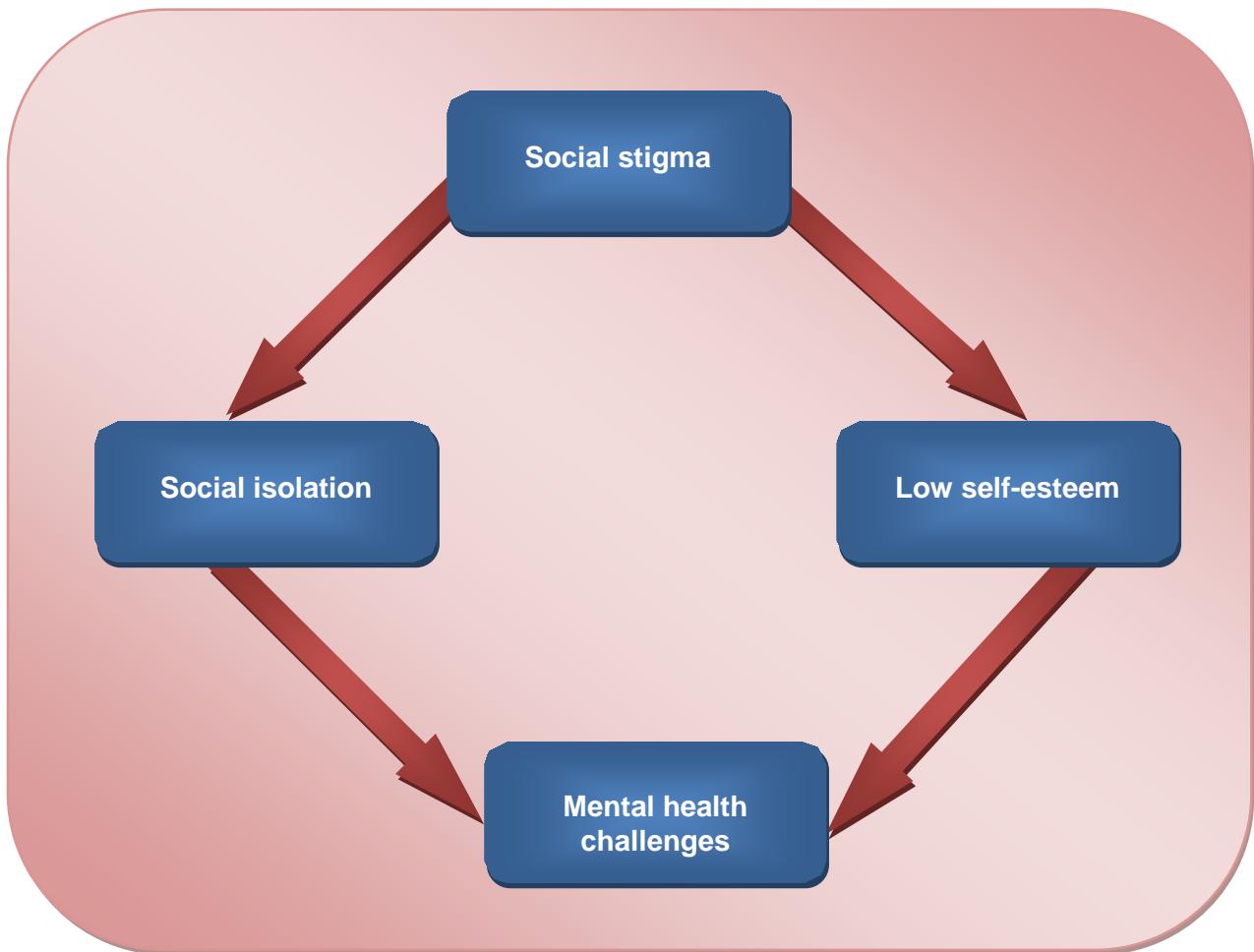


Figure 4.3 Relationship among mental health challenges and social stigma

(Adapted from Xiaoming, Stanton, Fang & Lin 2006:14-31)

- **Social stigma**

Boyd (2008:2) describes stigma as a mark of shame, disgrace or disapproval that results in an individual being shunned or rejected by others. Stigma has important consequences for the way in which individuals come to see themselves. The separation implies a process of devaluation and discrimination against the stigmatised group. In this study, the participants reported that the mentally ill patient undressed in public, roamed around naked, talking alone and insulting people. One participant said:

"Then, when he comes back one would observe that he smoked dagga by his uncontrollable laughter, speaking to himself and moving "up and down" here at home. He would even take off his clothes and remain stark naked. He would look for an elevated area and stand there so that everyone could see him. He makes a laughing stock of himself."

According to Xiamong et al (2006:14-31), stigma is considered an attribute used to separate affected individuals from the normalised social order of life.

- **Social isolation**

People with schizophrenia may have no friends, no spouse and sometimes no family. Palazzolo (2005:227) found that family members are isolated. They receive very little education as to what they can expect. Families of mentally ill patients bear the burden of care outside the hospital. As time goes on, the family become more isolated feel more and more frustrated, helpless and hopeless, even though they care about the patient (Keltner et al 2003:327). In this study the mentally ill patient had a family that participated, although the patient was not married. The participants indicated isolation also by the mentally ill patient as a sign of relapse:

"It is when he does not come out of his room. He would sleep for abnormally long hours. He would even forbid me from entering his room."

According to Hooley (2010:238-242), one of the defining characteristics of schizophrenia is impaired social functioning, with social isolation and withdrawal.

- **Low self-esteem**

Self-esteem refers to how positive the self image is or how satisfied a person is with relating and their being (Uys & Middleton 2010:24). Low self-esteem is linked to dependency, the need for approval and a vulnerability to interpersonal problems and poor general health. Low self-esteem can be triggered or made worse by existing mental health problems or pressure of other symptoms and the stigma associated with mental health problems (Uys & Middleton 2010:24).

- **Mental health challenges**

A mental health challenge is any disease or condition affecting the brain that influences the way a person thinks, feels, behaves or relates to others and to the surroundings. The study revealed that the participants experienced a heavy burden in providing care, leading to mental health challenges such as disruptions in family life, fear and concern.

- **Disruptions in family life**

Brady and Gail (2005:1-27) found that parents, spouses and siblings are often unable to deal with their own individual or family development needs because the focus is on the relative with schizophrenia. The family is often embarrassed by the symptoms and behaviours of the mentally ill member and avoids bringing other people home.

The participants expressed painful memories when thinking of the father as a suspect in causing the mental illness of two of his children. The participants indicated different witchdoctors that they visited seeking help for the disease:

“I used to work and what I worked for I cannot point. Now I am a pensioner. We took them to many places. There is no place or witchdoctor they do not know.”

“He took full responsibility for the family as he was working at Mabikiri Mine near Gravelotte. The problem started because of money. My father had a problem with him giving the money to our mother but not him. These things are caused by my father.”

The study revealed that the disruptions that occurred in this family were in relation to financial support. In their study, Prafulla, Murthy and Ramaprasad (2010:5-11) found that the participants did not regard disruption of family interaction and family leisure a severe burden. In this study, however, these areas greatly affected the daily activities of the family. Family members need referral to self-help groups or for counselling to maintain their emotional stability.

- **Fear and concern**

The aging parent of the patient had fear and concern about what would happen in the future, if she died. The participants showed concern about the frequent relapses that the patient had, and were concerned about the treatment plan and lack of financial assistance. The participants also grieved for the loss of the child they knew before the onset of the illness and who that child had become as an adult. According to one participant:

"It started when he was still at school in Grade 10 and he was one of the brightest in his class. This one used to be bright at school and would attend political meetings."

Gee et al (2003:11) indicate that families of mentally ill patients are often concerned about the future, how the illness will progress, not being able to plan their life and fears about further relapses.

Subcategory 1.3.3: Cultural factors

The way in which individuals deal with mental illness depends on how they understand and explain it (Uys & Middleton 2010:78). This was also true of the way in which the participants understood and dealt with the mental illness. Some families see mental illness as a brain disease, a hereditary disease, or as caused by witchcraft and substance abuse. Some families still believe that mentally ill people have been bewitched and are possessed by evil spirits (Uys & Middleton 2010:78). The diagnosis of mental illness in this family elicited feelings of guilt, concern over the prognosis and course of the disease, shame and embarrassment about the way in which people outside the family viewed the family and the patient. Society regards people with mental illness as dangerous, acting strangely and not reacting to people in a predictable way. Such perceptions are based on a lack of knowledge and understanding of what mental illness is and how it is treated (Uys & Middleton 2010:75). In this study, the participants believed that witchcraft was the cause of the mental illness with substance abuse as a precipitating factor. The participants understood mental illness in relation to heredity, witchcraft and culture.

- **Culture**

Culture refers to the attitudes and values which inform a society (*The Chambers English Dictionary* 2006:368). Keltner et al (2003:165) describe culture as the internal and external manifestation of a person, group or community's learned and shared values, beliefs and norms that are used to help individuals function in life and understand and interpret life occurrences. According to Uys and Middleton (2010:137), people's health care actions and cultural beliefs are generally formulated by three factors: their definition of health, their perception of the way in which illness occurs and their cultural worldview. People generally believe that illness has a cause and that cause differs; it may be viewed as resulting from natural, unnatural or scientific causes. An individual may believe, based on cultural background, that another person enlists the services of a magician, witch, ghost or supernatural being to cast a spell on others to cause illness. Witchcraft and sorcery in particular are seen to be the evil work of human beings who are, driven by envy and malice, to harm their fellow human beings (Uys & Middleton 2010:137).

The participants understood that there was a relationship between witchcraft and mental illness and that their patient's mental illness resulted as a punishment from the father. One participant indicated that the patient attended African National Congress (ANC) meetings, where he became aware that his father was on a list of people to become burnt in the community. When the patient reported this to the father, the father was very angry and after that the patient started to be mentally ill. According to the participant:

"When he came back from one of the meetings he informed our father that at the ANC meeting his name was mentioned as among those who were suspected of practising witchcraft. It started then, so we believed this has not been caused by outsiders; it is from within our family."

The father's behaviour towards the mentally ill patient made the participants suspect him of practising witchcraft. One participant indicated that the mentally ill patient was well treated by a traditional healer, but the father passed by the area where he was treated when the traditional healer was out and shook his son's hand. Later that day, the son showed signs of relapse, started undressing and calling his father:

"He extended his hand to greet him. Once he was touched by our father he just started taking off his clothes and when the traditional healer came home in the evening he found him just like that, and heard him saying "father ... father ... father ..."'

Boyd (2008:282) points out that efforts are made to consider culture when diagnosing and treating schizophrenia. Although symptoms are clearly defined, however, it is possible to find cultures in which what appears to be a hallucination may be considered a vision or a religious experience.

- **Heredity**

Heredity is the transmission of recognisable characteristics to descendants (*The Chambers English Dictionary* 2006:697). Several psychiatric disorders are presumed to have an important genetic component. Having a close family member with schizophrenia may be the largest contributor to the likelihood of the same disorder in the family (Uys & Middleton 2010:413). Uys and Middleton (2010:413) add that it is not clear what causes schizophrenia, although genetic factors produce vulnerability, with environmental factors precipitating the acute episodes of the disease. Children of schizophrenic patients have a 10% chance of developing schizophrenia.

The participants explained that there was no history of mental illness in the family although a brother who died in 2008 had also suffered from schizophrenia:

"It was not only him, but also our elder brother had the same condition of mental illness."

"From my maternal family there is no one who has this condition. Even from within my husband's family I do not remember anyone who is suffering from mental illness. This illness only came to him and his brother who passed away some years ago."

Sadock and Sadock (2007:470) state that the likelihood of a person having schizophrenia is correlated with the closeness of the relationship to an affected relative. Furthermore, the age of the father has a direct correlation with the development of schizophrenia. In families where there is no history of schizophrenia from both the

maternal or paternal line, it was found that those born from fathers older than 60 were vulnerable to develop schizophrenia (Sadock & Sadock 2007:471).

Schizophrenia poses numerous challenges in its management and consequences. According to Kannappan (2009:257-263), many families may be burdened and psychological stressed in caring for a mentally ill patient. Caregivers spend more time as they live with the patient and handle psychotic symptoms, behaviour problems and increasing care giving demands of the patient (Kannappan 2009:257-263). Families of people with schizophrenia tend to have inappropriate family cohesion and demonstrate poor communication patterns. Individuals with schizophrenia can be a disruptive influence on the family, particularly when they are non compliant with prescribed medication (Keltner et al 2003:327). Family involvement was a challenge to the participants although they understood their role in the care and treatment of the mentally ill patient. They had developed reasonable coping strategies and the challenges reported emanated after the patient's relapse. The participants still continued to provide support and care to the patient.

4.5 THEME 2: RELATING WITH THE MENTALLY ILL PATIENT

Relating with the mentally ill patient refers to the relationship of the mentally ill patient with the family; health professionals; members of the South African Police Service (SAPS); friends, and neighbours. The relationship is expressed in how they interact and values attached to the relationship process. Patients with long-term psychotic disorders lack social skills and this is a limiting factor in their rehabilitation. They have difficulty initiating conversations and are incapable of forming and maintaining friendships (Uys & Middleton 2010:430). Mentally ill patients are misunderstood, mistreated, discriminated against and made fun of. What they need is medical treatment and ongoing support from family, friends and the community. The mentally ill patient wants nothing more than to live a normal life, to be accepted and to make contributions. A positive attitude when relating with all patients, regardless of the diagnosis, is regarded as a basic necessity in the provision of care. The participants showed an understanding of the mentally ill patient's situation by continuing to provide care despite the unacceptable behaviour. People with schizophrenia often encounter challenges when it comes to relating with different groups of people around them. Table 4.4 indicates the findings on the mentally ill patient's relationships with others as reported by the participants.

Table 4.4 Relating with the mentally ill patient

Category	Subcategory	Meaning unit
2.1 Relationships with different groups	2.1.1 Relationship with the family 2.1.2 Relationship with health professionals 2.1.3 Relationship with members of the SAPS 2.1.4 Relationship with friends and neighbours	<p><i>"Even when his condition is worse, one needs to be near him even when he does not want people near."</i></p> <p><i>"The hospital is always doing its best because every time he comes from there he would be fine... at the hospital, he cuts his hair, wash himself and he is clean, there he eats and takes his tablets".</i></p> <p><i>"We were told that the hospital is overflowing with patients; they would release him even before he is well. To show that he is not well he would laugh and speak to himself, mentioning names of people as if he were speaking to them. He would do this the whole night and even during the day".</i></p> <p><i>"Every time he is in the hospital, it is the police who have taken him there"</i></p> <p><i>"You would be alerted by the neighbours of the things he had thrown into their yard".</i></p> <p><i>"... until one of the other gamblers took his grant card and ID and went to the bank to open an account where the grant money would be deposited".</i></p>

Category 2.1: Relationships with different groups

People with schizophrenia have a history of a schizoid or schizotypal personality, which includes solitary behaviours, detachment, inappropriate affect and lack of strong emotions (Fortinash & Worrel 2008:267). It is difficult for them to respond to normal social cues, initiate conversations, and develop relationships with others or become

productive members of society and this affects their relationships with different groups (Fortinash & Worret 2008:267). In this study, the participants reported relationships of the patient with the family, health professionals, and members of the SAPS, friends and neighbours.

Subcategory 2.1.1: Relationship with the family

Deinstitutionalisation increases stress on families caused by patients with schizophrenia returning home to live with inadequate community care and escalating readmissions. Fortinash and Worret (2008:652) state that many people with severe and persistent mental illness live with their families. The most common complaint amongst family members of a patient with schizophrenia is failing to understand how to help or give continued long term support.

In this study, one participant stated:

“Even when his condition is worse, one needs to be near him even when he does not want people near, we just force him to eat but he is not willing.”

Mthembu (2004:61) revealed that the majority of mentally ill patients reported that family members provided them with adequate clothing and food.

Family members of mentally ill patients shoulder a significant amount of care giving responsibilities, frequently with inadequate resources (Kotze 2007:27). The burdens of such care giving are multiple and pervasive. Kotze (2007:27) emphasises that family members need support to manage and accept the mentally ill patient at home.

Subcategory 2.1.2: Relationship with health professionals

Through effective communication and good relationship between mental health professionals and families of mentally ill patients, involvement in care will improve. Without effective communication between family members and mental health professionals there is inadequate assessment of the problem and limited or ineffective treatment or both (Uys & Middleton 2010:431). Uys and Middleton (2010:431) state that information relieves the anxiety of family members and gives them hope. Information

that must be given includes the symptoms of the disease, possible causes, prognosis and treatment that may be given. In this study, the participants' indicated that the level of communication and interaction with mental health professionals was generally good although communication regarding the need to discharge the mentally ill patient was insufficient. According to one participant, the patient was discharged early when he still had signs of mental illness:

“Sometimes when the hospital is overflowing with patients, the hospital would release him even before he is well. To show that he is not well, he would laugh and speak to himself, mentioning names of people as if he were speaking to them. He would do this the whole night and even during the day.”

Inappropriate mental hospital admissions are prevented through the provision of community alternatives for treatment, releasing institutionalised patients who had been given adequate preparation to the community (Boyd 2008:742). Fortinash and Worret (2008:269) identify the discharge criteria for a patient with schizophrenia as follows:

- Verbalise control of hallucinations.
- Have family willing to serve as a support network.
- Accept responsibility for self-care.
- Explain the importance of taking medication and their interaction with other substances such as food or alcohol.

The participants described both positive and negative experiences particularly with the nurses. According to one participant, nurses intervened when the mentally ill patient chased one participant in the hospital unit, although no other information was given with regard to symptoms and care of a patient with acute psychosis. Nurses are trained and equipped to deal with disease and sickness and to give information, however they failed to give an explanation when one participant indicated that the mentally ill patient was not yet fit for discharge. The participant was told that there were no beds in the unit, and no other information was given:

"We were told that the hospital was overflowing with patients; they would release him even before he was well. To show that he is not well he would laugh and speak to himself, mentioning names of people as if he were speaking to them. He would do this the whole night and even during the day."

In addition, the social worker did not follow up on the patient's disability grant. The study found that the participants shouldered responsibilities with inadequate assistance and information from health professionals at times.

Subcategory 2.1.3: Relationship with members of the SAPS

People experiencing psychosis are sometimes violent, especially when their illness is out of control or they stop taking medication (Stuart 2009:342). The participants indicated that the police service was of good assistance to them, as soon as they heard the name of the mentally ill patient, they rushed to the participants' home because they knew how dangerous the patient was. The *Mental Health Care Act, 17 of 2002* (South Africa 2002:44) stipulates that "if a member of the SAPS has reason to believe, from personal observation or from information obtained from a mental health care practitioner; that a person due to mental illness or severe or profound intellectual disability is likely to inflict serious harm on self or others, the member must apprehend the person and cause that person to be taken to an appropriate health establishment administered under the auspices of the State for assessment of the mental health status of that person". The findings indicated that the members of SAPS complied with section 40 of the Act (South Africa 2002:44). The participants confirmed the assistance by members of the SAPS as follows:

"I just run to the police station and request their help. The local policemen already know about him, when we mention his name they just come quickly."

Jonsson (2008:83) revealed that more than half of mentally ill referrals by members of the SAPS were male, due to the fact that males present with dangerous behaviour which is more likely to attract the attention of the police when notified by the community members. The male patient in this study also presented with a history of substance abuse and unacceptable violent behaviour (Jonsson 2008:83).

Subcategory 2.1.4: Relationship with friends and the neighbours

- **Friends**

The participants reported that the mentally ill patient's friends could not understand schizophrenia and quickly lost interest in continuing their friendship with him especially when their sympathy for the condition deteriorated. The participants revealed that friends gave the mentally ill patient dagga although it is not safe for the individual:

“One of his nephews cautioned the friends for giving him the dagga.”

One participant indicated that one of his friends opened a bank card for the patient secretly in order to have access to the disability grant money as indicated in the following statement.

“One of the gamblers took his grant card and ID and went to the bank to open an account where the money would be deposited. He did this in order to have access to the money immediately when it was deposited. Even as we speak, my brother’s ID is with that man.”

Friends can be supportive or abusive to a mentally ill patient. Mthembu (2004:67) found that acceptance by people promotes recovery. At the same time, mentally ill patients exposed to substance abuse may be tempted to use substances which may lead to relapse.

- **Neighbours**

The community may regard patients with schizophrenia as unrewarding to manage in view of their handicaps and poor response to treatment. Wood and Edwards (2005:279) found that mentally ill patients experienced more victimisation when compared with the experiences of a similar life style risk group. Patients with schizophrenia who do not receive adequate care can turn violent and pose a risk to themselves and others. One participant indicated the relationship of the patient and community as follows:

“When his condition is stable, he relates well with them but when it worsens, he would not want any person near him. He would even insult them when they greet or try to talk to him. He would also throw stones at them.”

In this study, the mentally ill patient related well with the community unless there were signs of relapse. According to Fortinash and Worret (2008:267), the behavioural disturbance of great concern is the possibility of violence, which increases when mentally ill patients have a co-existing alcohol abuse, substance abuse and an antisocial personality. Fortinash and Worret (2008:267) state that clients in the community who are most likely to be violent with relapse need mandatory outpatient treatment programmes.

In this study, the participants indicated that the mentally ill patient related well with the family, health professionals, members of SAPS, friends and neighbours except when there was a relapse.

4.6 CASE STUDY

The advantage of using a case study method was the detailed level of analysis that resulted because the research was confined to a small number of subjects (Brink et al 2008:110). Although the findings of the study cannot be generalised as only a single case was involved, other researchers can draw conclusions that can enhance further valuable empirical studies.

The researcher used constructs, concepts and statements from the findings to develop a conceptual map to explain variations and identify gaps in the findings and existing literature (Burns & Grove 2007:179). Figure 4.4 depicts the conceptual map.

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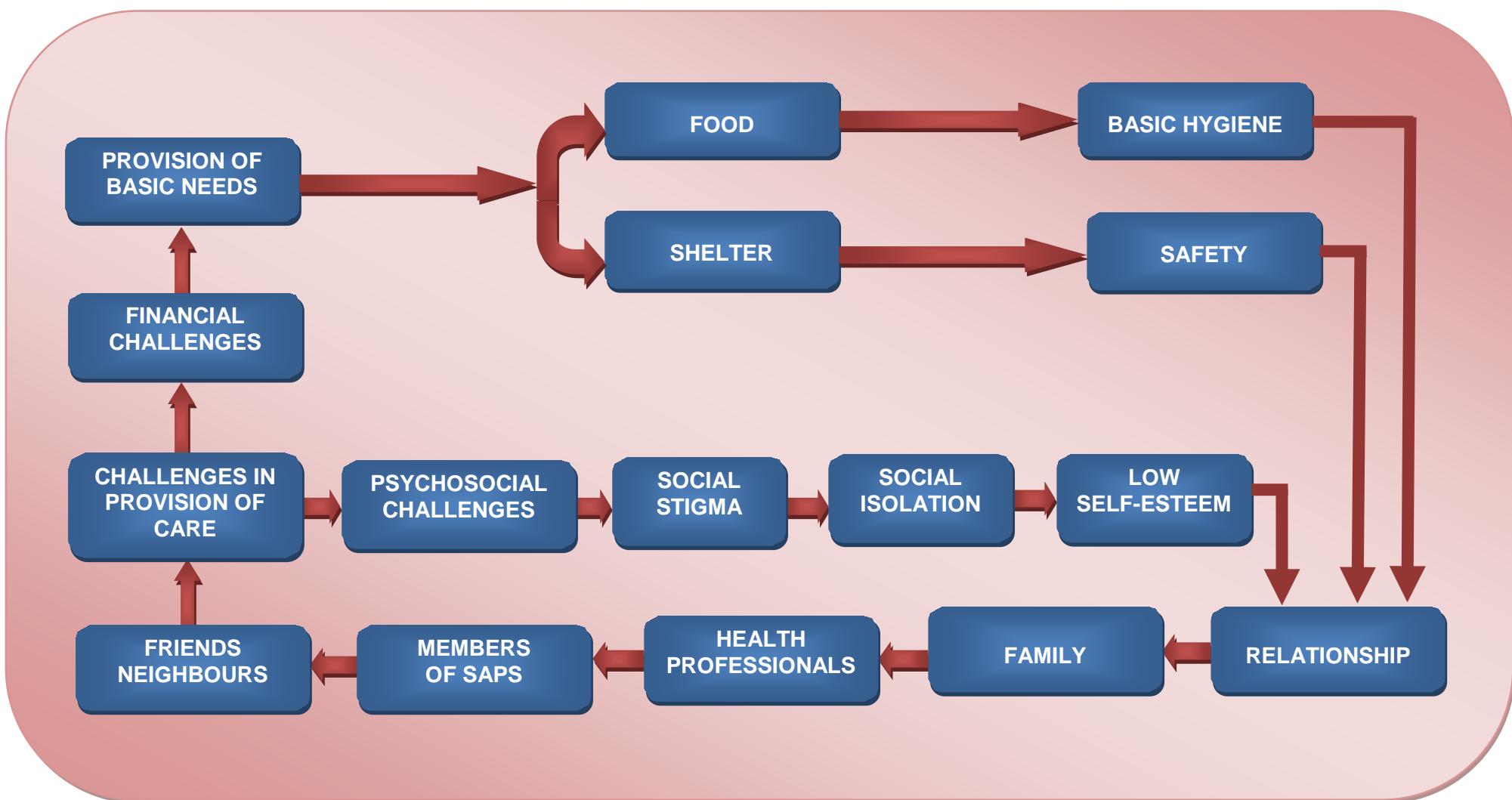


Figure 4.4 Conceptual map constructed from the study findings

Figure 4.4 indicates that schizophrenia poses numerous challenges in its management and consequences. Provision of care to the mentally ill patients poses numerous challenges to the family members. Whilst basic care was provided to the patient, the relationships between different groups were affected either positively or negatively. The affected relationships resulted in challenges in the provision of care which again affected the optimal attainment of the patient's needs especially in the home environment. Although the genogram was available to evidence the family structure, identification of biological, genetic, early psychosocial factors, developmental and pre-morbid history was not available to fully understand the experiences of the family caring for the schizophrenic patient (Uys & Middleton 2010:203).

4.7 CONCLUSION

This chapter discussed the data analysis and interpretation. The major themes, categories and subcategories that emerged from the data were tabled and discussed, and a conceptual map drawn that captured the findings.

Chapter 5 presents the findings and makes recommendations.

CHAPTER 5

CONCLUSIONS, LIMITATIONS AND RECOMMENDATIONS

5.1 INTRODUCTION

This chapter dealt with the conclusions, limitations and recommendations. The major research findings as presented in the preceding chapter were discussed in relation to the relevant literature. The recommendations based on the findings of the study were also presented.

The question that plagued the researcher was: "What are the experiences of family members caring for a long-term mentally ill patient?" Therefore the researcher's main objective and purpose of the study was to explore and describe the experiences of the family members caring for a long-term mentally ill patient.

5.2 CONCLUSION ON THE MAJOR FINDINGS

The findings of this research were based on the objective of the study and were discussed in context. The researcher conducted a case study based on the qualitative, exploratory and descriptive study design about the experiences of family members caring for a patient suffering from schizophrenia. Data was collected using an interview guide with one grand tour question. The sample consisted of four members of a schizophrenic patient's family who was cared for at home after several re-admissions to the psychiatric hospital. Data was analysed using Tesch's (1990) steps of qualitative analysis cited in Creswell (1994:155). This section provides an integrated summary of discussions and conclusions of the findings as obtained from the data.

5.2.1 Conclusion in relation to experiences in provision of care

The way in which people deal with mental illness depends on how they understand and explain it. It is true in this study in the way in which the family members dealt with the mental illness (Uys & Middleton 2010:89). Families act as caregivers and in the African

context caregiving is a family affair with multiple caregivers, a system that allows the primary caregiver time of relief from caring. It was evident in this study also that the four family members were caring for the mentally ill patient and the mother was the primary caregiver. Families looking after a family member with a mental illness usually do this due to the emotional bond between them, because they perceive it as their duty , they feel guilty and often they don't have a choice (Uys & Middleton 2010:89). However, the participants' responses revealed significant factors that hampered the provision of care to the mentally ill patient. The participants believed that the mentally ill patient was ill because he has been bewitched by his father.

When a family has a member with mental illness, the family's functioning changes, to accommodate the mentally ill relative. Although, the family is helpful to provide a full and detailed report of the mentally ill patient that can assist in diagnosis, family members may not know how to respond to the symptoms of mental illness. Almost without exception, normal life becomes disrupted and chaotic with the advent of schizophrenia (Fortinash & Worrel 2007:139). The dysfunction continues for a lifetime, often worsening over time. The world becomes unpredictable and challenging for the mentally ill patient , the family and the community with regard to human suffering , loss of productivity and economic expenditures (Fortinash & Worrel 2007:139). Although, psychiatric treatment has progressed remarkably in the last decades and allowed schizophrenic patients to rejoin society , giving them hope and a will to continue living and functioning in meaningful ways, complete recovery from schizophrenia is the exception rather than the rule (Fortinash & Worrel 2007:139). However, participants in this study developed coping strategies that enabled them to continue to provide care to the mentally ill relative despite the challenges experienced.

The difficulty that was experienced was poor compliance to treatment and substance abuse that led to relapses and frequent readmissions to the psychiatric hospital. Although a patient with schizophrenia is vulnerable after a period of stability to return to the symptoms and the disease itself revolves around a pattern of relapse and recovery (Kneisl & Trigoboff 2009:377). Often, the care givers were concerned about the frequent relapses.

Boyd (2008:60) states that physiological needs for food and shelter must be met before caring for the symptoms of mental illness. However, participants in this study revealed

that refusal to eat accounted for a lot of frustration before giving the mentally ill patient medication. The participants were further concerned about poor personal hygiene, the mentally ill patient neglected to bath, change clothes and comb his hair. It was difficult for the participants to assist the mentally ill patient to bath, although ways to motivate the patient were employed. The findings of this study concurs with literature in Kneisl and Trigoboff (2009:386) that schizophrenic patients may neglect to bath, change clothes or attend to minor grooming tasks such as combing the hair. Fortinash and Worrel (2007:139) further state that schizophrenic patients wear strange clothing, such as an overcoat in summer, avoids personal hygiene and contact with others. Diminished drive, flat affect and disturbances of thought are reasons why the mentally ill patients have difficulty in accepting responsibility for self care (Uys & Middleton 2010:425). However, the mentally ill patients should be supported to improve their personal appearance and to be helped to dress neatly and appropriately.

Although violence is not a consistent behavior of persons with schizophrenia, it is always a concern when hallucinations and delusions may put the patient at risk to harm themselves or others. The participants reported violence during a period of relapse and it was difficult to manage the patient except with the assistance of members of SAPS. Substance abuse was indicated as a precipitating factor to the violent behaviour.

5.2.2 Conclusion in relation to psychosocial support

Emotional burden is the impact of the care-experience on the mental and emotional well being of the caregiver, for instance an elderly mother becoming worried and afraid of her son who tends to be aggressive during acute episodes of mental illness (Uys & Middleton 2010:90). A study conducted by Corrigan and Miller (2004:537-548) revealed that parents are blamed for causing mental illness , siblings and spouses are blamed for not assuring the relatives with mental illness to adhere to the treatment plans . Children also are fearful of being contaminated by mental illness. Findings in this study also reflected that the participants were blaming their father for causing the mental illness in the family. Another psychosocial challenge experienced by the participants was stigma attached to mental illness. Stigma is based on a lack of knowledge and understanding of what mental illness is and how it is treated (Uys & Middleton 2010:85). This is part of the reasons why persons with mental illness cannot find work, housing or friends. Family stigma is the prejudice and discrimination experienced by individuals through

association with a mentally ill relative (Larson & Corrigan 2008:87-91). Stigma impacts negatively on the family members' care for a mentally ill patient. The participants reported that the patient would remain naked, and look for an elevated place and stand there so that everyone would see him. Thus the family experienced stigma which increased as the patient's behavior differed from cultural norms. Stuart (2009:180) states that the patients and their families report that the diagnosis of a mental illness is followed by increasing isolation and loneliness as family and friends withdraw. Stigma, misunderstanding and fear surrounding mental illness are related to both the people and agencies providing mental health services and the people receiving these services (Stuart 2009:180).

Reducing stigma must involve the following programmes:

- talking about mental illness in the community
- public education on mental health issues
- contact with persons with mental illness through schools and other social institutions
- providing support and effective treatment services for persons suffering from mental illness (Stuart 2009:180)

The lack of work, inability to work and lack of a desire to work are all features of schizophrenia. Uys and Middleton (2010:435) state that schizophrenic patients have a poor work record due to lack of drive, limited interpersonal and social relationships, lack of job experience and job specialisation. Schizophrenic patients who work are hospitalised less frequently than those who do not work (Uys & Middleton 2010:435). Therefore, a job can contribute to more effective functioning. In this study financial challenges started from the time that the disability grant was stopped. Some of the patient's friends secretly utilised the disability grant .It was difficult for the family to provide for the mentally ill patient especially when the patient requested money to buy dagga before taking medication. Financial burden is a challenge to the family as it results in challenges in the provision of basic needs as depicted in figure 4.4 of the conceptual map.

Families are burdened with a long-term responsibility of caring for a mentally ill relative, and they may suffer disruptions in their household routine. The participants revealed the

visits to different witch doctors seeking for help against the mental illness. Time off was needed to accompany the schizophrenic patient to doctors' appointments, make hospital visits and help during interviews with the hospital or police.

Culture shapes the behavior of people, including their behavior in health and illness. The culture of a society refers to the learned, shared and transmitted values, beliefs, norms and patterns for behaviour characteristic of a particular social group. Culture guides a group's thinking, decisions and actions in patterned ways (Uys & Middleton 2010:156). The findings of the study revealed that the participants expressed their understanding of the relationship between culture and mental illness. African people make a difference between naturally occurring illnesses and mental illness, since they will not in the first instance consult Western health care providers. The findings of the study reflected the participants' belief in witch doctors because they first consulted them, although they also consulted Western health care providers later. However, Boyd (2008:282) states that efforts are made to consider culture when diagnosing and treating schizophrenia. One participant excluded genetic factors as contributory factors to the occurrence of mental illness in the family. Although they understood that having a close family member with schizophrenia, may be the largest contributor to the likelihood of the same disorder in the family.

5.2.3 Conclusion with regard to treatment and relapse

Mentally ill patients may refuse treatment because of many reasons. Symptoms such as delusions and denial may cause refusal to take treatment. The findings of the study indicated poor compliance to treatment and substance abuse that led to relapses and frequent readmissions to the hospital as a challenge to the family. One participant requested the use of injectables to improve compliance as supported in Sadock and Sadock (2007:489) that compliance increases when long acting medication is used instead of oral medication.

Relapse is caused by a range of factors, both internal and external to the patient. Uys and Middleton (2010:280) identified the variables related to relapse as health, environment and behavioral factors. A patient with schizophrenia is vulnerable after a period of stability to return to the symptoms. The disease itself has a pattern of relapse and recovery (Kneisl & Trigoboff 2009:377). Participants were concerned with relapses.

However, they developed coping strategies that enabled them to continue to provide care to the mentally ill relative. Furthermore, Uys and Middleton (2010:280) suggested coping strategies that the patient and family can implement, although many of the strategies are under the control of the patient. In this study relevant coping strategies based on the findings were identified as follows:

- Good nutrition
- Enough sleep
- Good compliance to medication
- Avoid the use of illegal drugs such as dagga

Good nutrition, enough sleep and good compliance to medication are positive promoters of health , whereas the use of illegal drugs is negative and should be discouraged at all times because it leads to instability and interferes with positive symptom management (Uys & Middleton 2010:281). The inclusion of the family in the treatment process greatly reduces the relapse of mentally ill patients.

5.2.4 Conclusion with regard to relationships

Different groups of people relate differently with mentally ill patients. In the African traditional way of “ubuntu” a human being is viewed as a collective being, as part of a family which includes the extended family. A person is also seen as part of the community, as well as part of the ethnic group (Uys & Middleton 2010:158). The family as a group plays an important role in the functioning of a patient and all family members should take responsibility for the patient’s rehabilitation. The findings of the study indicated support that was provided by all family members to the mentally ill patient. The participants perceived that the relationship with the mentally ill patient in the family, with health professionals, members of SAPS, friends and the community was good due to the support that was provided.

The findings revealed good relationship between family members and health professionals as supported by Uys and Middleton (2010:187) that the nurse does not only build a relationship with the patient but also with the family or primary caregivers. Health professionals’ roles are to give support, listen to the family in order to assess their burden and avoid blaming family members for the occurrence of the mental illness.

Information with regard to mental illness, causes and treatment must be conveyed in understandable terms in order for the family to apply it meaningfully. Members of the SAPS were also reported to be of assistance to the family. Communities are uninformed about schizophrenia and this hampers the rehabilitation of the patient and their integration into the community. The participants reported friends who provided the mentally ill patient with dagga as a way of maintaining friendship, which precipitated signs of relapse. One friend who was also involved in the patient's disability grant, abused the friendship by cheating the patient financially which resulted in financial constraints in the family. Fortinash and Worret (2007:142) state that patients with schizophrenia who have compromised insight and judgment from the disorder are victims of ruthless drug peddlers. Patients may spend their income on drugs instead of medications, rent or food. Patients may further be abused emotionally, psychologically, socially, morally and physically (Fortinash & Worret 2007:142).

5.3 CONCLUDING REMARKS

A family caring for a mentally ill patient has a powerful influence on the individual patient and can help by providing a full and detailed picture of the individual's history that can help with the diagnosis and assist with monitoring and supporting the treatment effort. Family members who are well informed about the diagnosis and treatment plan of the mentally ill patient are able to support the mentally ill patient to live successfully in the community although they need information and training to perform their roles.

5.4 RECOMMENDATIONS

The study findings highlighted some important challenges experienced by the family which needs follow up and actions to be taken to improve caring for long-term mentally ill patients. In addition, the study identified gaps in the ways of how to care for the patients as identified by the conceptual map and validation with literature. Based on the findings, therefore, the researcher makes the following recommendations for education of family members and health professionals, and further research.

Education of family members

Family members seem not to have the basic information that they need to guide their decisions on the care of the mentally ill relative. The study revealed that family members delayed taking the patient to hospital when he has relapsed.

Family members should therefore:

- be exposed to relevant educational programmes or workshops that will empower them to provide care to schizophrenic patients
- be engaged in teaching programmes whose content should include side effects of prescribed medication, signs and symptoms of relapse
- be empowered on coping strategies, what to do in case of violence, refusal to take treatment and relapse

Education on health professionals

Health care professionals and family members have the same goal of patient care, therefore:

- the relationship between them should be strengthened, so that information about patient care can be shared with the family
- health professionals should advocate for the enhancement of community-based programs to help integrate mentally ill individuals into the community

Training and personnel development either in curricula or in-service education programs to include development of nursing care plans for family or care givers of patients with long-term illness should be conducted.

Further research

There is a need for more empirical processes to be implemented to investigate the experiences of family members or care givers of mentally ill patients at home. The quantitative method will be ideal and done with larger population sizes.

Suggestions also for future research is a study addressing the role of siblings and children in caring for and supporting the mentally ill person, because the patient's illness affects not only the patient and the parents, but also the entire family, especially siblings and other family members living in the same household.

The study emphasised the importance of educating family members, health professionals and the patient on elementary concepts of care. However, families are expected to provide support to their relatives who are mentally ill in the community without adequate and necessary information on how to provide such care.

5.5 LIMITATIONS OF THE STUDY

Generalisability: Qualitative researchers do not specifically seek to make their findings generalisable, but seek understanding that might prove useful in other situations (Polit & Beck 2008:202). Data was collected from four participants and as a small sample size does not permit firm conclusion, the generalisability of findings from naturalistic inquiries is called into question (Polit & Beck 2008:17). This may also have implications to data saturation as in qualitative studies data is collected until saturation. Only four participants were interviewed and it was not easy as some of the participants were asked questions repetitively in order to satisfactorily answer the research question.

5.6 CONCLUSION

Firstly, although the small sample size does not permit firm conclusions, fundamentally these findings suggest that family members caring for a mentally ill patient are faced with myriad challenges in provision of care. There is a connection between mental illness and life experiences of care givers. Mental health professionals need to look beyond the individual patient but also care about the family in the diagnostic and treatment process. They need to pay attention to the whole individual, which includes the individual's family. The family can be helpful because they can provide a full and detailed picture of the individual and that can help in diagnosis, monitoring and supporting the treatment. Effective management of mental illness by family members will ease the burden that the health system is currently experiencing.

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Annexure A: Approval from the university: Ethical Clearance Certificate



**UNIVERSITY OF SOUTH AFRICA
Health Studies Higher Degrees Committee
(HSHDC)
College of Human Sciences
ETHICAL CLEARANCE CERTIFICATE**

Date of meeting: 10 February 2011 Project No: 3217-848-4

Project Title: Experiences of family members caring for a long term mentally ill patient

Researcher: Nshalati Clarah Banyini

Degree: MA in Health Studies Code: DIS702M

Supervisor: Dr LV Monareng

Qualification: D Litt et Phil

Joint Supervisor: -

DECISION OF COMMITTEE

Approved

Conditionally Approved

Prof E Potgieter
RESEARCH COORDINATOR

Prof MC Bezuidenhout
ACADEMIC CHAIRPERSON: DEPARTMENT OF HEALTH STUDIES

PLEASE QUOTE THE PROJECT NUMBER IN ALL ENQUIRIES

Annexure B: Letter seeking consent from the Department of Health: Limpopo Province

Enq.N.C. Banyini
Cell no.:079 504 7681
082 821 5204

P.O. BOX 1940
LETABA
0870
08 APRIL 2011

The Head of Department
Department of Health and Social Development
Private Bag x9302
POLOKWANE
0700

Sir / Madam

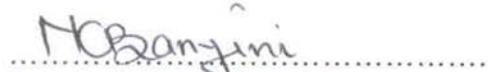
REQUEST FOR PERMISSION TO CONDUCT A RESEARCH STUDY

I am a student at the University of South Africa currently registered for MACUR, and hereby request permission to conduct a research study.

The title of the research is: EXPERIENCES OF FAMILY MEMBERS CARING FOR A LONG TERM MENTALLY ILL PATIENT AT LETABA HOSPITAL.

The research proposal and ethical clearance certificate from the University are included.

Yours truly,


Nshalati Clarah Banyini

08/04/2011
Date

Annexure C: Letter seeking consent from Letaba Hospital

Enq.N.C. Banyini
Cell no.:079 504 7681
082 821 5204

P.O. BOX 1940
LETABA
0870
21 November 2011

The CEO
Letaba Hospital
P.O. BOX X1430
LETABA
0870

Sir / Madam

I hereby request permission to identify one family of a long term mentally ill patient in the hospital records for research purposes. The study is titled:
Experiences of family members caring for a long term mentally ill patient at Letaba hospital.

I am currently an MA (Cur) student with the University of South Africa (UNISA). My supervisor is Doctor Monareng L.V, Department of Health Studies at UNISA.

Attached is the ethical clearance certificate from the ethics committee of the Department of Health Studies UNISA. Approval to conduct the study was also obtained from the Department of Health, Limpopo Province.

The benefit of the study to the hospital is that the summary of the research findings will be used to formulate guidelines for the support of family members caring for long term mentally ill patients.

Hoping that the request will be considered.

Yours truly,


Nshalati Clarah Banyini (MACUR student UNISA)

21/11/2011
Date

Annexure D: Letter of approval: Department of Health: Limpopo Province



DEPARTMENT OF HEALTH

Enquiries: Selamolela Donald

Ref: 4/2/2

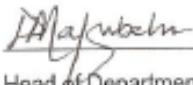
22 July 2011
Banyani NC
University of South Africa
Pretoria
0001

Greetings,

Re: Permission to conduct the study titled: Experiences of family members caring for a long term mentally ill patient in Letaba Hospital

1. The above matter refers.
2. The permission to conduct the above mentioned study is hereby granted.
3. Kindly be informed that:-
 - Further arrangement should be made with the targeted institutions.
 - In the course of your study there should not be any action that will disrupt the services
 - After completion of the study, a copy of the report should be submitted to the Department to serve^s as a resource
 - You should be prepared to assist in the interpretation and implementation of study recommendations where possible

Your cooperation will be highly appreciated



Head of Department
Department of Health
Limpopo Province

Annexure E: Letter of approval from Letaba Hospital



**DEPARTMENT OF HEALTH AND SOCIAL DEVELOPMENT
LETABA PROVINCIAL HOSPITAL**

Private Bag X1430
Letaba
0870

Ref: 4/2/2/
Enq: Mabuza MF
Date: 23 January 2012

Banyini NC

P.O.Box 1940
Letaba
0870

**RE: APPROVAL FOR CONDUCTING A RESEARCH ON EXPERIENCES OF FAMILY
MEMBERS CARING FOR A LONG TERM MENTALLY ILL PATIENT IN LETABA
HOSPITAL**

1. The above subject matter refers:
2. You are granted permission to conduct the above research at Letaba Provincial Hospital as per permission granted by the Head of Department, Limpopo Department of Health .
3. Hoping that you will find this to be in order.

A handwritten signature in black ink, appearing to read "Mpho Mabuza".

CHIEF EXECUTIVE OFFICER/ LETABA HOSPITAL

Tel: 015 303 8200 • Fax: 015 303 0207

The heartland of southern Africa - development is about people

Annexure F: Informed consents

F[i] Informed consent letter for adult participants

Dear research participant: CONSENT TO PARTICIPATE IN A STUDY

I am an MA (Cur) student with the University of South Africa (UNISA). I am conducting a research study titled: **Experiences of family members caring for a long term mentally ill patient in Letaba hospital.**

The main aim of the study is to determine the experiences of family members caring for a long term mentally ill patient. To complete the study, I need to conduct an individual interview with family members between the age of 10 – 60 years both male and female.

The interview will be audio-taped for verification of findings by the supervisor and anonymity will be maintained by not using names and places. There is no material benefit for participating in the study; it is only an opportunity for family members to share experiences in caring for a long term mentally ill patient. Findings of the study could however be used to draw a programme to assist family members caring for a long term mentally ill patient.

Should you wish to contact the researcher for enquiries, feel free to do so at the following address: Ms N.C Banyini, P.O. Box 1940, LETABA, 0870 Cell no. 079 504 7681

I hereby voluntarily give consent to participate in the study. An explanation about the study: **Experiences of family members caring for a long term mentally ill patient** has been given to me.

I understand that my identity will not be made known, all information shared will be kept confidential and that I may withdraw to participate in the study anytime I so wish.

.....
Signature of the Participant

.....
Date

.....
Signature of Witness

.....
Date

.....
Signature of Investigator

.....
Date

F[ii] Informed consent letter for minors

Dear research participant: CONSENT TO PARTICIPATE IN A STUDY

I am an MA (Cur) student with the University of South Africa (UNISA). I am conducting a study titled: **Experiences of family members caring for a long term mentally ill patient in Letaba hospital.**

The main aim of the study is to determine the experiences of family members caring for a long term mentally ill patient. To complete the study, I need to conduct an individual interview with family members between the age of 10 – 60 years both male and female.

The interview will be audio-taped for verification of findings by the supervisor and anonymity will be maintained by not using names and places. There is no material benefit for participating in the study; it is only an opportunity for family members to share experiences in caring for a long term mentally ill patient. Findings of the study could however be used to draw a programme to assist family members caring for a long term mentally ill patient.

Should you wish to contact the researcher for enquiries, feel free to do so at the following address: Ms N.C Banyini, P.O. Box 1940, LETABA, 0870 Cell no. 079 504 7681.

I (Mother, father, guardian)
of..... hereby voluntarily give consent of her / his participation in the study.

An explanation about the study: **Experiences of family members caring for a long term mentally ill patient** has been given to us.

I understand that our identity will not be made known, all information shared will be kept confidential and that he / she may withdraw to participate in the study anytime he / she so wish.

.....
Signature of (Mother, father, guardian)

.....
Date

.....
Signature of Witness

.....
Date

.....
Signature of Investigator

.....
Date

Annexure G: Questionnaire and Interview Guide

QUESTIONNAIRE ON THE EXPERIENCES OF FAMILY MEMBERS CARING FOR A LONG TERM MENTALLY ILL PATIENT

SECTION A: BIOGRAPHICAL QUESTIONNAIRE

Biographical data of family members

1. Gender

Female	
Male	

2. Age: 10 – 60 years

0-10	
11-20	
21-30	
31-40	
41-50	
51-60	

3. Marital status

Married	
Single	
Divorced	
Widow	
Widower	

4. Qualifications

Primary level	
Secondary level	
Tertiary level	
Other	

5. Employment status

Unemployed	
Employed	
Self employed	

6. Relationship to the mentally ill person

Father	
Mother	
Brother	
Sister	
Son	
Daughter	
Other	

7. Duration of care

0-2 years	
3-4 years	
5-6 years	
> 7 years	

Biographical data of mentally ill patient

1. Gender

Female	
Male	

2. Age

11-20	
21-30	
31-40	
41-50	
51 -60	
>60	

3. Marital status

Married	
Single	
Divorced	
Widow	
Widower	

4. Qualifications

Primary level	
Secondary level	
Tertiary level	

5. Employment status

Unemployed	
Employed	
Self-employed	

6. Specific diagnosis of the mentally ill patient

Schizophrenia	
Other	

7. Period of mental illness

0-2 years	
3-4 years	
5-6 years	
>7 years	

SECTION B

INTERVIEW GUIDE

GRAND TOUR QUESTION

"Tell me what your experiences were as you were caring for your mentally ill relative?"

Examples of probing questions:

- Tell me about the experiences in caring for a long term mentally ill patient.
- What challenge do you experience when caring for a long term mentally ill patient?
- How do you handle the challenge in provision of care of the mentally challenged family member?

Annexure H: Editor's letter

Cell/Mobile: 073-782-3923

53 Glover Avenue
Doringkloof
0157 Centurion

27 August 2012

TO WHOM IT MAY CONCERN

I hereby certify that I have edited Nshalati Clarah Banyini master's dissertation,
**EXPERIENCES OF FAMILY MEMBERS CARING FOR A LONG TERM
MENTALLY ILL PATIENT AT LETABA, LIMPOPO PROVINCE**, for language and content.

IM Cooper
192-290-4

Annexure I: Interview transcripts

INTERVIEW TRANSCRIPTS

The interview was conducted at the home of a mentally ill patient.

PARTICIPANT 1

Interviewer: What lessons have you learned while caring for your relative who has mental illness?

Participant: I do understand the situation because it is long that we have been living with him in this condition. Some of the things we only got to understand during the process of caring for him. He is a type of a person who when it (his condition) has started he does not even come out of the house and will not speak to anyone. During this state he would not even eat. When it is like this, one would realise that the condition is worsening, what he needs most is cigarette instead of food. He would demand money for his cigarette, and when one says there is no money, he would suddenly become violent and chase everybody away from the house. He would not even take his prescribed medication until he has smoked. We just force him to eat but he is not willing.

Interviewer: From your explanation, I realised that you emphasise the issue of him not willing to eat and also his substitution of food for cigarette. What have you learned in terms of the relationship between food and cigarette during the times when his condition is worsening?

Participant: I learnt that when he smokes his condition becomes worse and as such he would even leave home, no one would touch or control him. When he is outside the home, he would even smoke "big" cigarette and when he comes back, he would be so destructive and uncontrollable. He would smash (destroy) the household utensils, even those that he bought himself while he was still receiving his disability grant. He has also destroyed his own bed.

Interviewer: What do you mean by the "big" cigarette?

Participant: This is the dagga that they smoke when he is outside. Then, when he comes back one would observe that he smoked dagga by his uncontrollable laughter, speaking to himself and moving "up and down" here at home. He would even take off his clothes and remain stark naked. He would look for an elevated area and stand there so that everyone would see him. He makes a laughing stock of himself. During this time no one would

reprimand / caution him, if one tries to reprimand him, he would become so angry and violent.

Interviewer: From what you have just pointed out, what is your impression of what actually triggers his condition (makes his mental state worse)?

Participant: What makes his condition worse is his reluctance to take his prescribed medication. When we tell him to take his medication, he refuses. He would only agree to take his medication only after we have offered him cigarette. When his condition has worsened, it becomes unbearable to us who cares for him.

Interviewer: How many times is he expected to take his medication (tablets) per day?

Participant: Three times a day. He takes them after his breakfast in the morning, after lunch in the afternoon and also in the evening after super.

Interviewer: Who normally gives him his tablets?

Participant: My mother is the one who gives him the tablets.

Interviewer: Apart from what you have already told me, what else have you learnt while caring for him?

Participant: I have learnt an important lesson in the caring for those with mental illness. Even when his condition is worse, one needs to be near him even when he does not want people near.

Interviewer: You have said that when he is in the “bad situation”, he is harassing everyone here at home. What are the particular issues you noted when he is harassing?

Participant: He destroys household utensils and furniture and throws them to the neighbours' houses. He also throws stones which can hurt. When he is like that no one approaches him, we leave him and he remains alone.

Interviewer: How is his relationship with your neighbours?

Participant: When his condition is stable, he relates well with them but when it worsens, he would not want any person near him. He would even insult them when they greet or try to talk to him. He would also throw stones at them.

Interviewer: What are the signs that show that his condition is moving from stable to bad?

Participant: It is when he does not come out of his room. He would sleep for abnormally long hours, and refuses to eat. When it is like this we easily see that the condition is changing from stable to bad. When he is well, he eats too much.

Interviewer: What have you done in order to seek help for all the problems you have explained?

Participant: The only help we normally get is that when the condition is bad, we call the police to take him to the hospital because he easily overpowers us. Every time he is in the hospital, it is the police who have taken him there. The local policemen already know about him, when we mention his name they just come quickly (faster) because they know we cannot handle him. Especially because you cannot hire people's car in his condition.

Interviewer: How does the hospital assist?

Participant: The hospital is always doing its best because every time he comes from there he would be fine.

Interviewer: When you say the hospital is doing its best, what actually do you mean?

Participant: When he is here at home, he does not even bath or cut his hair and his hair would grow long and disfigured because he does not comb it. When he is at the hospital, he cuts his hair, wash himself and he is clean. There he eats and takes his tablets. At the hospital he is controllable because when one speaks to him he is willing to listen. Normally, he would be fine just immediately when he is released from hospital.

Interviewer: Apart from his condition, who buys his food and clothing?

Participant: Oh! The situation is difficult here, because we all depend on mother's social grant. The rest of us are only doing seasonal jobs which do not last longer. So we do not have any other source of income. Initially, he used to receive his disability grant, which assisted in him buying clothing, food and whatever he wanted but now his grant has been terminated. My mother is now responsible for everything, and she cannot afford. He is now suffering because he does not have any financial assistance.

Interviewer: I heard you saying, when he was still receiving his grant, before it was terminated. How come the grant was terminated?

Participant: I was married for sometime and was no longer staying at home, although it was not far, and I used to visit and check. When the patient's condition was worse I was full time at home. Even when his condition was worse, he would not forget to go and collect his grant.

But he would use the money for gambling (with dice) until one of the other gamblers took his grant card and ID document and went to the bank to open an account where the grant money would be deposited. He did this in order to have access to the money immediately when it was deposited. Even as we speak my brother's ID document is with that man. This made my mother and uncle to be very angry and they approached the social workers and his doctor and told them that he was no longer accountable to his money. So his grant was terminated.

Interviewer: From your observation is there any difference in his condition during the times he used to receive his grant money and now that he is no longer receiving it?

Participant: During the time he used to receive his grant money, the condition would become worse but it was controllable. Though there were moments that his condition would be so bad that he was uncontrollable, he was able to use his own money to get whatever he wanted. But now that he is no longer receiving his grant money, when his condition is worse, it is also difficult for him to get things that he wants because he does not have money.

Interviewer: How often does he relapse within a year?

Participant: In the past he would be fine for at least four month after having spent some time in the hospital. Now it does not last that longer, from the time of his release from hospital, he would be fine for less than two (2) months.

Interviewer: When last has he actually relapsed?

Participant: A month before last month. Normally when he relapses, we do not immediately take him to hospital; we wait and observe a little longer whether the tablets cannot assist. But when he is taken to the hospital and he is given "that" injection he suddenly becomes fine. He even spent the New Year's Day at the hospital but when he came back this January he was well.

Interviewer: Apart from relying from the assistance of the hospital, are there no other "things"/ places where you seek help from as you were saying you do not just immediately take him to hospital when he relapses?

Participant: Initially we wasted a lot of money by taking him "from one place to another" in some places he stayed for longer but his condition did not improve. Having realised that there was no help coming from "those" places, as a family we decided to rely only on the hospital.

Interviewer: What do you mean by "from one place to another"?

Participant: I mean the inyangas (traditional healers).

Interviewer: When you went to visit him in those places, how was he like?

Participant: He would be well but once he came back home, his condition would worsen.

Interviewer: Are there any other things you would like to explain in terms of what you face as you try to assist him?

Participant: No, but I observe that with the care of the hospital, he is now fine. The only thing we should do is not to lose courage in assisting him to take his tablets. Even when he insults us, we just keep quiet, he will get tired.

Interviewer: As you observe from the times that you have been together, what would you say are the causes of his condition?

Participant: It was not only him, but also our elder brother had the same condition of mental illness. But with him, it started when he was still at school doing grade 10 and he was one of the brightest in his class. During those days, the ANC used to rally people to move around and clean the area and they would warn those parents who were alleged to be practicing witch-craft to stop it or else they would be burnt. When he came back from one of the meetings he informed our father that in those ANC meetings his name was mentioned as among those who were suspected to be practicing witch-craft. It started then, so we believe this has not been caused by outsiders; it is from within our family.

Interviewer: Is the father your real biological father?

Participant: Yes, he is our father. My brother's fault was to speak the truth by telling our father that he was also on the list of those who were to be burnt. My father was afraid that his son was knowledgeable and feared that he would invite the "comrades" to burn him. This was not the case; my brother's intention was to warn our father. From the day it started, he never went to school. My father later passed away and left him just like that.

Interviewer: When did your father pass away?

Participant: My father died in 2001.

Interviewer: When he was still alive, as your brother was now mentally ill, how did your father feel about your brother's condition?

Participant: My father did not care. He would even tout our brother by making remarks such as "your brains are now gone, how would you go to school and learn". Sometimes my father would not speak to him even though they lived in the same household.

Interviewer: You said he was not the only one who was sick here in the family. The other brother who also had the same condition, what actually happened to him?

Participant: He passed away in 2008, not long ago. He was born in 1964. He grew up well and started working, and he took full responsibility of the family as he was working at "Mabikiri" mine near Gravelotte. The problem started because of money. My father had a problem with him giving the money to our mother but not him. These things are caused by my father. The police used to come and pick-up the two brothers and take them to hospital for treatment. Even that one was as uncontrollable as this one when the condition was worse.

Interviewer: These brothers, were they twins or siblings?

Participant: He was the second-born in our family.

Interviewer: This brother who was born in 1964, how did he become mentally ill?

Participant: As we grow up he was well as he was working but suddenly he changed and even stopped working. This matter affected us badly because when he was sent to hospital, he came back well but immediately he found employment, he would not spend a week there, he would relapse. With him when the condition was worse, he would not talk, bath or eat. What was more painful is that he would not sleep the whole night, he would be moving around the yard until sunrise.

Interviewer: When he died what were the actual causes of death?

Participant: The doctors said he died due to ulcers. He used to smoke a lot of dagga. We just grew up knowing him to be smoking dagga. Ultimately his lungs were damaged. He would vomit something spongy like pieces of liver.

Interviewer: How did the two brothers treat each other since they were both mentally ill?

Participant: They really loved each other and treated each other well. When one was supposed to go for check-up at the hospital, none of them was willing to go alone, they accompanied each other there. They would always be saying "my brother, my brother". They stayed together and shared their secrets. The younger one would never disclose where his grant card was even when taken by the other gamblers. But at least the elder one would tell us that it was taken, and that they opened a bank account so that they could access the money whenever they wanted. Even when their conditions were bad, the elder one would not insult his younger brother but the younger one would insult his elder brother. The elder one would always be close and next to his younger brother even when the younger one has relapsed. This was not the case with the younger one.

Interviewer: Are there any other things you would like to explain relating to your mentally ill brother?

Participant: No, the only thing that we want is help so that he could again get his disability grant. He is giving us trouble here at home, there is no peace. He becomes so angry that he causes us a lot of pain. During those days that he used to get his grant money, he was able to afford those things he wanted. We do not have the money to buy him "All Star" takkies. With his grant money he used to buy for himself.

Interviewer: Did you try to ask the people at the hospital to fill the relevant forms for him so that you would submit to the SASSA?

Participant: I do not know whether my mother has done this because she is the one who take him to the doctors. She is the one who told the doctors that the money is not received by him but by others who do not even assist him with anything.

[The researcher thanked the participant and promised to make a follow-up with her should there be anything related to what transpired during the interview]

PARTICIPANT 2

Interviewer: What are your experiences during the process of caring for your brother who has been mentally ill for a long period?

Participant: When he relapses, he takes off his clothes and remain stark naked. When he is given food, he just throws it away. He would throw stones at us or anything he finds, we just run away.

Interviewer: According to you what actually caused his illness?

Participant: This comes from within the family.

Interviewer: When you say it is from within the family, could you explain how?

Participant: It started because our father did not like our brothers to be working. He "harmed" them and suddenly one day when coming from school he was a different person, no longer "normal". He used to work in the local town by assisting people pushing their

grocery trolleys. When my father realised he was working, he made him the way he is today. So he just became mad.

Interviewer: I have heard you saying that he also harassed you?

Participant: He would chase all of us away until we slept somewhere. Our neighbour will find him naked.

Interviewer: What have you observed might be the trigger to his relapse?

Participant: When he came from hospital there was another man who gave him cigarette mixed with nail polish. After smoking, he became worse again. Also when he smokes the “green cigarette” he relapses.

Interviewer: What else have you encountered as you cared for him?

Participant: Most of these I have already explained.

Interviewer: When you say it all started here in the family, what else would you explain in terms of how it all started?

Participant: Some of these things I could not recall because they happened while I was still very young. But what I know is that it started in the family.

Interviewer: During these years that you have been living together, do you have any other things that you could explain apart from the fact that he throws stones at you and chase you away from the family.

Participant: He just throws food away and takes off his clothes.

Interviewer: How do you assist him?

Participant: We take him to the hospital and when he comes back he is fine. But once he goes outside the yard and gets that “green cigarette”, he becomes worse.

Interviewer: From what I have gathered, would I be right when I say he becomes worse after he has smoked?

Participant: Yes, especially with dagga, it becomes worse. He would stop taking his tablets and refuses to go for check-up to the hospital.

Interviewer: Who gives him the money to buy cigarette?

Participant: He is given by other people in the street. My mother used to buy him the cigarette called "BB" after she received her pension money. She would only give him a small ration everyday. But once he moves out, people outside gives him dagga. When he comes back his eyes would be blood-red.

Interviewer: What actually made your mother to buy him "BB"?

Participant: He used to trouble her, so she decided to buy him "BB" because she says it is not as harmful as the green one.

Interviewer: Apart from his condition. How are you able to help him?

Participant: We buy him clothes and food.

Interviewer: Are there any other specific challenges you come across as you help him?

Participant: No.

Interviewer: How does the hospital assist you?

Participant: The hospital helps us when we fail to manage his situation here at home.

[The researcher thanked the participant and promised to make a follow-up with her should there be anything related to what transpired during the interview]

PARTICIPANT 3

Interviewer: Which lessons have you learnt during your process of staying and caring for your uncle who is mentally ill?

Participant: My uncle would just take off his clothes and remain naked. Sometimes when we give him food, he would throw it away. He also wet his bed when his condition is worse. He insults those who give him food.

Interviewer: What other things do happen here at home which is related to his condition?

Participant: He smokes dagga. Sometimes, when he comes home his eyes are blood red. He would throw furniture away.

Interviewer: What do you do when the situation is like this?

Participant: My grand-mother would go to the police station and then comes back with the police who would take him to the hospital.

Interviewer: How does he relate with all of you here at home?

Participant: He just moves up and down. He also refuses to take his prescribed tablets. Ever-since he came back from hospital he does not bath.

Interviewer: Who gives him his tablets?

Participants: My grandmother and I are the ones who normally do this.

Interviewer: How many times do you give him his tablets in a day?

Participants: Three times a day.

Interviewer: When you give him his tablets, what actually happens?

Participant: Now because his condition is stable he does take his tablets.

Interviewer: When he has relapsed what actually happens?

Participant: He would remain asleep for abnormally long hours, destroy household utensils, walk around during the night while naked and would not bath.

Interviewer: According to your observation what triggers the relapse?

Participant: It is dagga.

Interviewer: When he has not smoked dagga, how is he like?

Participant: He does not insult.

[The researcher thanked the participant and promised to make a follow-up with her should there be anything related to what transpired during the interview]

PARTICIPANT 4

Interviewer: Which lessons have you learnt as you cared for your son who is mentally ill?

Participant: His issues are that as soon as he relapses we take him to the hospital. Once admitted to the hospital, it normally takes a week for him to be fine. When his condition has worsened when one tries to move next to him, once he says "no, go away" he would not change his mind. He would even chase me away claiming that he does not know me and refuse to take food from me. The nurses in the hospital will tell him that she is your mother, but he will refuse and says he does not know me. The nurses will eventually tell me to give them his food and let me go home. He will say that he will not eat the food, but the nurses will tell me that he will eat when I am away. I generally recognise it in his eyes if he is well or not. When he is well, his eyes are in their humane position but once not well his eyes appear protruding. I have even told the doctors in the hospital that I am able to know whether he is well or not just by looking at his eyes. Sometimes when the hospital is overflowing with patients, they would release him even before he is well. To show that he is not well he would laugh and speak to himself, mentioning names of people as if he were speaking to them. He would do this the whole night and even during the day. Once well, people are surprised that was he the same person who was doing such things. When he is in his bad mood, he would eat his food in the bush or while walking in the street. When one gives him tea, he would take his mug and bread and eat while walking in the street. He would suddenly throw the cup away even before finishing the tea, and then we will go and pick up the mug.

Interviewer: What actually caused his mental illness?

Participant: From my maternal family there is no one who has this condition. Even from within my husband's family I do not remember of anyone who is suffering from mental illness. This illness only came to him and his brother who passed away some few years ago. They used to go together to the hospital. Sometimes if one of them left early for the hospital, the other would follow. The elder one had a wife and his daughter is already a mature woman, she already has a child. They stay with their maternal grandmother.

Interviewer: When I listened I understand that his brother had the same mental illness. Is that true?

Participant: The tragedy of my children, the elder one left on a contract to work in the mines in Carltonville. He had such a beautiful and hard working wife. The wife just changed when

he was at work, she moved from one family to another, we searched for her and found her and brought her home. She once went to her own family, and the husband sent her money but when we went to her home, we found she was not there. We had to inform the husband and he came home and that was the end of the marriage. He then married another woman. This one also eloped with another man.

Interviewer: As you have already explained that the two brothers had the same condition, what did you do to help them?

Participant: I used to work and what I worked for I cannot point. Now I am a pensioner. We took them to many places. There is no place they do not know. This one can even tell that he knows the house of Thomas Hasani Chauke (Xinyori); we passed there when we went to Mhinga. I fetched him there. We started at the hospital immediately when he was attacked by this illness. We tried with the African traditional doctors but to no avail. There was a certain traditional doctor who had just started the trade, I took him there. He came back well; he used to be the one who mixed the medicine for other mentally ill people.

One day his own father was taking his cattle to the grazing field, while passing next to the yard of the traditional healer, he extended his hand to greet him. Once he was touched by his father he just started taking off his clothes and when the traditional healer came home in the evening he found him just like that, and heard him saying “father...father....father....” The traditional healer was shocked because he left him well and could not understand what the father actually did to him and he said, “Oh, his father realised he was well, so he came to bring back the illness”. It would not matter where one would send him, even though he would be healed while there, but once he came back home, his condition would just deteriorate. The things that my husband used to say about him, created a lot of suspicion. It was difficult when they grew up, I struggled with their upbringing. I did all the menial jobs just to ensure they grew up well.

Interviewer: Just as you said he was well while in that traditional doctor up until he was greeted by his father, how was the relationship between the two of them (father and son)?

Participant: They used to respect their father. They would not utter anything negative against him or do anything bad to him. He used to lie to people that he was a healer. He said he had supernatural powers. When he came here at home things would start, I have never seen such things ever since I was born. I saw that he had things and the children just became mentally ill. The one who passed away used to buy us food. His only sin was his own money and the other's was his school (education). This one used to be bright at school and would attend political meetings. He once came from those meetings and told his father to stop the “things” he was doing in order to save his father from the comrades. The father's reaction was to bewitch my son. My son never insulted his father, he was just warning him.

Interviewer: Ever since he was attacked by this illness, what is your opinion of what actually triggers his relapse?

Participant: It is the dagga that he smokes. These illnesses are dangerous if mixed with dagga. If he were to quit smoking dagga, he would be well. His going to the hospital and the tablets would not help him because of the dagga. His friends exacerbate his condition because they give him dagga. One of his nephews cautioned the friends for giving him the dagga.

Interviewer: What are the signs of the things he does here at home to show that he is suddenly relapsing?

Participant: You can see that window, it is his room, and he broke the window pane. He breaks the chairs and throws them to the neighbours. You would be alerted by the neighbours of the things he had thrown into their yard. He damages his own trousers; he no longer has a proper pair of trousers.

Interviewer: How does he treat you when his condition is bad?

Participant: Hey! I cannot even speak to him. He would insult me and tell me the most hideous insults. He would chase me away, then takes off his clothes and remain naked. He would even forbid me from entering his room. When I see these things, I just run to the police station and request their help. They would come and find him sitting in the veranda only clothed by a blanket. I would tell the policemen that he does not have his clothes on and I would enter the house and pick up the trousers and give them.

Sometimes he would refuse and ask the police a lot of questions. They would tease and praise him and tell him to go with them, he would refuse. They would tell me that they have a spray and they would spray his eyes and pick him and load him into the police van. When his condition is bad he does not want me near him, he accuses me of witchcraft and being the one who is trying to kill him. If I was responding to his accusations, he should have injured me long ago.

Interviewer: That he is about to relapse what are the indications?

Participant: It is obviously his eyes, his eyes would change. But you can see him now, he is fine. When one notice his eyes protruding it is obvious his almost relapsing.

Interviewer: Who actually assist him here in the family with day to day needs?

Participant: It is his nephew, though they sometimes argue because of his refusal to bath. Ever since he came back from the hospital two months ago he has never bathed. When you give him water to bath, he would say I would do it, but he would take clean clothes and put them on without actually bathing. What would I do to such a grown up man, he is not a child whom I can simply put in the basin. His nephew also gives him clothes.

Interviewer: Do you greet each other when you wake up in the mornings?

Participant: Sometimes we do greet each other. But it depends on his mood. Sometimes he would send the young ones to do very difficult tasks, if they fail, he would insult them. I once took his matter to the local induna after I realised that what he did to me was not proper. I went to my sister's funeral but when I came back I found that he had dug in front of the door and put some herbs so that I die. I found these herbs while I was sweeping the yard hidden under some stones. I took the matter to the induna. When he is well he is the first to greet me but once he relapses and his condition is bad it can take a month before we actually speak to each other.

Interviewer: How does the hospital help you?

Participant: They always give us proper care. Once send to the hospital, he comes back home well.

Interviewer As you have said that the dagga is the key trigger of his condition, what did you do to help?

Participant: There is nothing we could do. He would smoke and then relapses and we had to run to the police station.

Interviewer: Where actually does he get the dagga?

Participant: The whole of this village is littered with dagga. They buy it in a match box.

Interviewer: Where does he get the money to buy the dagga?

Participant: He asks from his friends. Some I have tried to chase.

Interviewer: Are there any other issues relating to him that you want to explain?

Participant: There is not much. But from the year before last he is no longer receiving his grant money. His ID document is with the one who is abusing his money. When I tell him to go and collect his ID document, he refuses.

Interviewer: Why is he no longer receiving the disability grant money?

Participant: Those people opened a bank account for him in town where the money was then deposited and they had access to the money without informing us. So we informed the social worker. In the hospital they also said he relapses because of money. The social

worker recommended that his disability grant be stopped because it was not longer assisting him.

Interviewer: Have you noticed any difference in the manner of his illness from the time he was still receiving his grant money and now that he is no longer receiving it?

Participant: When he has his own money, he is able to buy himself what he wants.

Interviewer: Since the social worker recommended the termination of his grant, how do you manage his care here at home?

Participant: I know it is difficult. I only receive R1000 and I have to buy everything. There is none to assist me.

[The researcher thanked the participant and promised to make a follow-up with her should there be anything related to what transpired during the interview]